Online Parental Accounts Regarding a Multimodal Intervention for Neurobehavioral Disorders: A Qualitative Descriptive Study

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ABSTRACT

The purpose of this qualitative inquiry was to describe parents' experiences of the Brain Balance Program, as revealed in their online writing. This study provides a description of parents' experiences in a way that highlights what participating in the program was like, asserts their judgements about this program, describes the impact of the program on the parent and child and describes the parents' motives for doing the program and motives for writing about the experience. Six online documents were chosen that were information rich and showed a maximum variation of viewpoints. The sample of online documents were written by parents and retrieved from online sources in November, 2012. Basic Qualitative Descriptive research (Merriam, 2009) was used to design the study and qualitative content analysis was used to produce the findings. Content analysis is "a research method for the subjective interpretation of the content of text data through systematic classification process of coding and identifying themes or patterns" (Hsieh & Shannon, 2005, p. 1278). The findings provide a thick description of parents' perspectives on their experience of helping their child through a multimodal program for neurobehavioral disorders. Limitations, implications and areas of future research pertaining to the study are discussed. This study can inform parents' decision making around interventions and provides support for further research in biomedical and cognitive rehabilitative approaches for neurobehavioral disorders.

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To my boys, thank you for cheering me on, as no one else can, and for reminding me of what really matters.

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DEDICATION

For Hawkeye and Magoo

Cassius and

The Fabulous Six

and all the others who walk the same path you were given,

your courage and perseverance amaze me.

Hebrews 12:12-13

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CHAPTER 1

These are hopeful times. Basic research in neuropsychology has the potential to be applied to practice in schools and to transform interventions for neurobehavioral disorders. Research evidence supports the neurobiological basis of many disorders such as Learning Disabilities, Attention Deficit/Hyperactivity Disorder and Autism Spectrum Disorders (Freberg, 2010); these understandings are stimulating the development of interventions that will impact families and schools (D'Amato, Fletcher-Janzen & Reynolds, 2005). Throughout the history of education and psychology many interventions have been offered as possibilities in treating, or coping with neurobehavioral disorders and over time these interventions have been evaluated and then implemented or abandoned (Wolff, 2004; Gersten & Dimino, 2006). Effective interventions are still being sought for individuals with neurobehavioral disorders. The Brain Balance Program (Melillo, 2009) (hereafter "Brain Balance") is an example of a recent intervention being promoted to parents that is based on premises from neuropsychological research. Brain Balance has been promoted online, on the book shelf, at Autism conferences and in communities in the United States where Brain Balance Achievement Centers run the program. This study was concerned with reviewing online parental postings which describe parents' experiences and personal evaluations of Brain Balance.

1.1 Initial Wonderings about Brain Balance

Initially, I came across Brain Balance in my local bookstore when I spied Disconnected Kids by Robert Melillo, 2009. Curiosity led me to peruse it. The program was described online as

> ...an individualized and comprehensive approach to helping children with neurobehavioral disorders and learning difficulties surmount their unique challenges. This proprietary, non-medical program has been successful in helping thousands of kids reach their physical, social/behavioral, health and academic potential. We work with children who suffer with ADD/ADHD, Dyslexia, Tourettes, Asperger's and Autism Spectrum Disorders. (Is brain balance right for your child?, n.d.)

Robert Melillo (2009) proposed that many neurobehavioral disorders stem from a functional disconnect in the brain, that is, there are problems in the connectivity of the brain or how the brain is wired. His Brain Balance program proposed to help rewire the brain by using sensory/motor exercises, academic exercises and nutrition to reduce impairments so that they no longer could be classified as a neurobehavioral disorder (Melillo, 2009). I wondered about the efficacy of this program and other similarly premised programs. I wondered how this intervention related to other interventions that had neuroplasticity as one of their rationales. Neuroplasticity is the ability of the nervous system to change its structure and function throughout life (Miniussi & Vallar, 2011) Neuroplasticity informs programs such as the Arrowsmith Program for Learning Disabilities by Barbara Arrowsmith-Young (Arrowsmith-Young, 2012) and therapies for brain injured individuals. I was intrigued by the ongoing development of rehabilitative methods for brain injured individuals. Many cases have shown remarkable unanticipated gains from rehabilitative therapies. These stories create optimism that new methods that stimulate neuroplasticity hold promise for treating neurobehavioral disorders, as well. Conducting research on parental experiences of this multimodal program has facilitated my understandings of interventions proposed to be related to neuroplasticity.

My interest in this research came out of my work experience with adults with significant mental health issues and with children with LD, AD/HD and Autism Spectrum Disorders. Additionally, my life experiences included being personally involved with individuals with neurobehavioral disorders. These connections made me very sensitive to the impacts of neurobehavioral disorders on individuals and their families. I was aware of the need for early intervention to avoid negative outcomes. I observed negative outcomes and cases that were well managed. I was familiar with the need of parents to seek effective interventions for their children and witnessed them be their child's biggest advocate. They benefit from guidance in evaluating interventions. Thus, I believed that it was important to do ongoing research into interventions and to evaluate experimental interventions.

I, like many, share the hope of finding solutions to the difficulties individuals with a neurobehavioral disorder face. I am intrigued by neuroplasticity and the relevance this has to neurobehavioral disorders. If it is proposed that an intervention can assist individuals to have freedom from or improved adaptation to their impairments then I think that this needs to be

investigated. I wonder if these interventions can be helpful. On the other hand, many are vulnerable to hoping, even wanting these interventions to be helpful. For example, families who have members with exceptionalities can be vulnerable to being persuaded by claims made about interventions. Claims can come from other parents who often share information about their experiences in supporting their child through an intervention. I was aware that accounts from users of an intervention can be influential and may be convincing to those who are vulnerable to the influence of these accounts. Yet, first-hand accounts can be rich sources of information and I thought the parental voice could be considered and honored as a source of information that contributes to the process of exploring interventions.

Although I found this intervention at a bookstore, Brain Balance has a strong online presence. Online forums and blogs are a rich source of parental voice regarding interventions. Online information about this multimodal intervention includes first-hand accounts of parents' journeys with their children. First-hand accounts can be valuable sources of information that can contribute to new understandings. Additionally, online information from parents about interventions can influence what methods other parents use in addressing their children's issues. Considering how online information influences consumers of interventions is important to ponder. How can consumers make use of this information and what other information should supplement it? As such, reviewing the online documents relating to Brain Balance was illuminating in many respects.

At the time of this study there were still many questions about Brain Balance that needed to be investigated as the research literature on this program was sparse. There was research that supports the idea that neuroplasticity is a reality and that connectivity problems are apparent in some neurobehavioral disorders, such as Autism Spectrum Disorders; yet the research on the efficacy of the Brain Balance intervention was limited and did not met the standard of evidence-based practice (Steele, Elkin & Roberts, 2008; Canadian Psychological Association, n.d.). At the time of this study only two small studies had been done on Brain Balance; therefore knowledge of the program was limited. Brain Balance had not been evaluated. As Brain Balance was already operating in many places in the United States, there were many parents who could share information about this program to contribute to its evaluation. This study explored what the

online stories of parents who had supported their child through Brain Balance, at a center, could tell about Brain Balance and multimodal interventions.

1.2 Research Purpose

The current study involved identifying and analysing a sample of online documents to understand the views of parents' of children with neurobehavioral disorders who had used Brain Balance. Experience has made me aware that some parents seek multiple approaches to try to assist their child. This often includes interventions from multiple professionals (speech-language pathologists, occupational therapists, psychologists, medical doctors, nutritionist, teachers) addressing multiple areas of impairment (language, sensory-motor, cognitive, academic, biochemical/physiological). Looking at online documents about Brain Balance allows parental views on this multimodal intervention to be examined. The purpose of this inquiry was to describe parents' experiences of Brain Balance, as revealed in their online writing. A description provides qualitative information that is useful to begin to evaluate the program, to better understand multimodal interventions and to consider the parental authors' purpose in producing an online document. The aim of this study was to be able to provide a description of parents' experiences of participating in the program, asserts their judgements about this program in meeting parent and child needs, describes the impact of the program on the parent and child and describes the parents' motives for doing the program and writing about the experience. Ultimately, this information may guide further research and inform parents' decision making.

1.3 Research Questions

The study was informed by the broad question: What do online documents reveal about parental experiences related to the multimodal intervention called Brain Balance? The sub-questions were (a) What is it like for parents and children participating in Brain Balance ? (b) What are parents' judgements about doing Brain Balance? (c) What are the impacts of Brain Balance on parents and children? (d) What motivates parents to do Brain Balance? and (e) What motivates parents to write about the experience online?

1.4 Definitions

Brain Balance Program- Is a combination of exercises (sensory, motor, and academic) and dietary changes implemented in an intensive schedule, with the goal of reducing the functional impairments of AD/HD, autism spectrum disorders, learning disabilities and other

neurobehavioral disorders. The proposed mechanism of change is neuroplasticity correcting a functional disconnect between cerebral hemispheres (http://www.brainbalancecenters.com).

Multimodal – Refers to using more than one mode or method of treatment (“multimodal”, n.d.).

Neurobehavioral – Of or relating to the relationship between the action of the nervous system and behavior (“neurobehavioral”, n.d.). In a neurobehavioral disorder there is dysfunction in the nervous system affecting behavior.

1.5 Organization of Thesis

The chapters of this thesis were laid out to give the reader a well rounded understanding of parental experiences with Brain Balance and the implications of this experience for wider research. Chapter 2 provides background information to facilitate the readers’ understanding of the findings. Chapter 3 details the research design of the study. The findings of the study are presented in Chapter 4 by providing a thick description in the parents’ own words. Finally, Chapter 5 summarizes the findings in relation to the research literature and discusses implications of the findings.

CHAPTER 2: BACKGROUND AND RATIONALE

The research literature that surrounds this topic is diverse because Brain Balance claims to address the needs of multiple disorders with methods that are attributed to neuropsychological understandings; therefore relevant areas of the research literature needed to be explored as a basis for understanding this topic and for understanding the importance of research in this area. The following chapter reviews the impacts of neurobehavioral disorders, current interventions used in a professional context, the context of parenting a child with a neurobehavioral disorder, related neurological research, research on neuroplasticity, and research on the sub areas of this multimodal intervention.

2.1 Disorder's Impact

Childhood neurobehavioral disorders such as AD/HD, Autism Spectrum Disorders and Learning Disabilities have a substantial impact on Canadian society and impair the functioning of the individual (Murphy, 2005; Szatmari, 2006). The autism spectrum consists of the following Pervasive Developmental Disorders: Autistic Disorder, Asperger's syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS); these disorders are otherwise known as Autism Spectrum Disorders (Wing, 1997 cited in Cumine, Dunlop and Stevenson, 2010). The autism spectrum consists of disorders of varying degrees of severity of three core symptoms. An individual with ASD has severe to mild impairments in social interaction, impairments in verbal and non-verbal communication and a manifestation of restricted, repetitive or stereotyped pattern of behaviors, activities and interests (American Psychological Association (APA), 2000). AD/HD is a neurobehavioral disorder that is characterized by developmentally inappropriate distractibility, hyperactivity and impulsivity (APA, 2000). Learning Disabilities refer to a number of disorders that affect the acquisition, organization, retention and understanding of verbal and nonverbal information (Mamen, 2007). There is significant co-occurrence of the symptoms of these disorders or co-morbidity of these disorders (Herbert, 2005; Kochar, Batty, Liddle, Groom, Scerif, Liddle and Hollis, 2010; Piek &Dyck, 2004). For example, children with ASD frequently have symptoms of hyperactivity and cognitive processing problems; while children with AD/HD frequently have co-occurring

learning disabilities and can have autistic features or Obsessive Compulsive Disorder (Barnard, Muldoon, Hasan, O'Brien, & Stewart, 2008; Herbert, 2005; Kochar, et.al, 2010). New models and findings in neuropsychology have emerged that explore the overlapping of symptoms of neurobehavioral disorders (Maddux & Winstead, 2008; Goldstein & Reynolds, 2011). To assist in understanding the need for continued research on these disorders and their relevant intervention it was helpful to review the prevalence of these disorders and the impacts they have on the individual, their family and society.

Prevalence rates for ASD, AD/HD and for Learning Disabilities indicate that neurobehavioral disorders are a significant mental health issue, that a significant proportion of the population is affected and that effective strategies for accommodating the needs of these individuals contributes to a just society. Prevalence rates refer to the number of individuals in a specific population at a specific time who have a specified disorder (Wing & Potter, 2002). In the case of learning disabilities prevalence rates are a broad estimate due to the heterogeneity of the disorders. The Learning Disabilities Association of Canada estimates that one in ten Canadians has a learning disability. In the US a national estimate for the years 2004 to 2006 indicated that 6-10% of school children had a LD (Pastor & Reuben, 2008). In the case of AD/HD, Faraone, Sergeant, Gillberg and Biederman (2003) analysed fifty international studies and found international consistency of a prevalence rate of 16% of the population for AD/HD symptoms and 7% of the population for symptoms of AD/HD with functional impairments (Farano et al., 2003). This similarity of prevalence rates internationally indicates that this is not just a cultural phenomenon and that a significant part of the population is impacted by this disorder. In regards to ASD, the occurrence of ASD happens more frequently in males, with the ratio of males to females being 4:1 for average I.Q. and 2:1 for those with intellectual disability (Goldstein & Reynolds, 2011). The prevalence of Autism in the U.S. in 2006 was 1 in 110 (Centers for Disease Control and Prevention, 2009). ASD in children who were 8 years old increased by 57% from 2002 to 2006 in 10 sites (CDC, 2009). In Canada, the trend of a rise in prevalence rates was similar to the U.S.; from 2003-2010 prevalence rates in Canada went up from a rate of increase of 39% to 204% (National Epidemiological Database for Study of Autism in Canada, NEDSAC, 2012). A significant trend for both countries is an increased prevalence of ASD in boys (CDC, 2009; NEDSAC, 2012). Recent reviews put prevalence rates of classic autism at 13 per 10,000, PDD-NOS at 20.8 per 10,000 and Asperger's syndrome at 2.6 per 10,000; for a total of

approximately 36.4 per 10,000 individuals (Goldstein & Reynolds, 2011). The increased prevalence rate has raised concerns as to the possibility of an environmental cause (Wing & Potter, 2002). Although the possibility of a true increase cannot be ruled out, the increase may be the result of increased awareness of ASD, healthcare providers with increased awareness of symptoms or change in diagnostic criteria (to further complicate this analysis the anticipated DSM-5 will have changes to diagnostic criteria for ASD) (Wing & Potter, 2002). Needless to say a significant portion of the population is impacted by neurobehavioral disorders.

The impacts of neurobehavioral disorders are diverse and outcomes vary depending on severity of the disorder, and the interventions and resources available to the individual at key moments of development. Even though there are a range of outcomes associated with these disorders, all of these disorders have challenges that require the individual to cope and as a result they are at increased risk of adverse outcomes. For example, those with LD are known to have higher rates of depression, anxiety and suicide (Wilson, Armstrong, Furrie & Walcot, 2009). Additionally, the impact of AD/HD and LD is varied and can include the following: greater health care needs, increased injury, employment difficulties, psychiatric issues (Visser, Bitsko, Danielson, Perou & Blumberg, 2010); negative impacts on academic achievement, lowered levels of education (i.e. increased dropout rates) (Schottekorb & Ray, 2009); lower social status among peers (Kavale & Furness, 1996); increased likelihood of developing substance abuse (Faraone et al., 2003) and lowered self-esteem and increased development of secondary problems (e.g.depression) (Selikowitz, 2004). In regards to ASD, by 13 to 17 years of age 40% of children with ASD have had at least one serious episode of depression or anxiety disorder (Szatmari, Bryson & Boyle, 2004). In addition, 25% of individual's with ASD have epilepsy with the attached risk of premature death, 60% have a mental health problem such as AD/HD, depression or anxiety disorders; 50% are non-verbal as adults; all have cognitive difficulties with 50% having mental retardation and 60% take psychotropic medication (Szatmari, 2006). As adults those with ASD have varied outcomes some good but many poor, in terms of independence and employment. In a past review, approximately 20% (although this number is rising) of adults with ASD who were employable had difficulty finding and keeping work and often held jobs below their education level (underemployment) (Volkmar, 2007). Also, the majority with ASD did not live independently but relied on family or community supports (Volkmar, 2007). A review of outcomes in adults with ASD indicated that longitudinal studies post 1980 show only 12% lived

independently (Volkmar, 2007). Services needed for assisting adolescents and adults with ASD in transition into adulthood, community life are lacking in many communities and contribute to poorer outcomes (Szatmari, 2006; Goldstein & Reynolds, 2011). Better outcomes are correlated with speech by the age of 5 and an I.Q. of 70 and above (Volker, 2007). The challenge of coming decades will be to provide the services that support individuals with ASD via early intervention for children and support and transition services for adolescents and adults (Volker, 2007).

Additionally, parents and siblings are affected by behavioural problems and the needs associated with neurobehavioral disorders. Parents of children with AD/HD and ASD tend to have increased levels of stress, depression and marital discord compared to the general population (Faraone et al., 2003; Volkmar, 2007). Families of children with ASD tend to experience considerably more stress than parents of children with other developmental disabilities and as a result are at risk of having more mental health problems (such as depression) compared to parents of other disabled children (Bromley et. al, 2004). While neurobehavioral disorders pose a challenge/risk that may lead to adverse outcomes there is variation in how families cope with the challenge. Many show positive adaptations and ongoing research works to better understand this resiliency (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001).To foster positive adaptation, it is essential to respond effectively to the needs of these exceptional children and their families.

2.2 Current Interventions

Responding to the impact of neurobehavioral disorders involves finding effective treatments and providing access to them. The following is not a comprehensive review of all the possible interventions for LD, AD/HD or ASD but is an overview of the more common approaches currently recommended for individuals with these disorders. When faced with the developmental challenges of their children, interventions are sought by parents and schools.

The state of interventions for ASD can be bewildering to parents because there are many competing voices and areas of research, additionally there can be limited resources and a shortage of adequately qualified professionals available to help. Governments and groups concerned with providing appropriate services reviewed research literature and came to diverse conclusions on how to proceed (Dillenberger, 2011). That is

these various groups reviewed different literature, used different

> definitions of 'evidence-based', lumped or split interventions at different levels of specificity (e.g., treatment protocols vs. broad principles), and, not surprisingly, came to different conclusions. As a result, although there is *some* (although not universal) consensus about *some* aspects of interventions for *some* sub-groups of individuals with autism, particularly young children (e.g., National Research Council, 2001), there really is no agreement within the field about what constitutes effective, evidence-based treatment for the entire range of people with autism (Mesibov & Shea 2011, p.119)

Clearly, it is challenging for parents when seeking interventions because service providers are still finding their way in understanding treatment effectiveness and developing appropriate programs.

Interventions for ASD funded by governments have been diverse and fall into the general categories of the 'eclectic approach' and the Applied Behavior Analysis (ABA) approach (Dillenburger, 2011). Governments in Europe have tended to endorse (exception Norway) the eclectic approach, while North American governments have tended to endorse the ABA approach. The eclectic approach occurs when governments fund a range of interventions applied according to need (Dillenburger, 2011). Eclecticism is criticized on the grounds that (1) some interventions have an evidence base while others do not or may even be controversial; (2) there is limited understanding of differentiating between synergistic effects of multiple interventions and the effects of a particular intervention and (3) the lack of a coherent theoretical base to guide therapy (Dillenburger, 2011). Eclecticism may draw from an array of interventions and can include a combination of ABA techniques (usually Discrete Trial Training), Sensory Integration Therapy, Floortime, Lovaas, TEACCH, Son Rise, Hanen Programme, biomedical and special education (Dillenburger, 2011). On the other hand, the eclectic approach has been seen as being child-centered and responsive to the various presentations of ASD. In addition, some would see eclectism in ASD as helpful in spurring more diverse research than just enshrining one discipline and theoretical viewpoint as the only evidence-based intervention (Mesibov & Shea, 2011; Perry & Condillac, 2003).

Applied Behavioral Analysis (ABA) is known as the 'technology' of the science of behavior analysis and there are decades of research supporting the effectiveness of ABA with diverse populations, for diverse behaviors and in diverse settings (Perry & Longenecker, 2007). Practitioners of ABA systematically apply empirically derived interventions that are based on behavioral principles to improve meaningful behaviors, in a way that demonstrates that the

intervention was responsible for the behavior change (Perry & Longenecker, 2007). ABA can be used to teach new skills, reinforce and maintain skills; generalize behavior to multiple situations; restrict or reduce conditions under which interfering behavior occurs (e.g. modify environment); and reduce interfering behavior by discontinuing reinforcement and reinforce competing replacement behavior instead (Perry & Longenecker, 2007). Different methods used in the ABA approach are discrete trial training, precision teaching, natural environment teaching, pivotal response training, procedures based on verbal behavior, picture exchange systems, shaping and chaining, incidental teaching, and task analysis and prompting (Dillenburger, 2011). Some have critiqued the ABA approach as being too narrow, inflexible, a rigid single approach (often equated with discrete trial training) (Dillenburger, 2011), unethical in its previous use of aversives and restraints (Dawson, 2004) and an approach that does not work for all young children with ASD (Fitzpatrick, 2009). ABA advocates would clarify that when ABA is implemented by properly trained practitioners that it is an individually tailored program that uses diverse methods and that research confirms the effectiveness of ABA for contributing to desired change in intellectual functioning, social skills and communication skills (Dillenburger, 2011). Currently, ABA does not generally use aversives but has found other behavioral procedures (altering the environment, reinforcing replacement behavior) to reduce aggressive or self injurious behavior (Volkmar, 2007). There can be a misunderstanding that ABA is the equivalent of discrete trial training (DTT) but ABA can include more than this. The misunderstanding comes when in some special education programs discrete trial training is used as a segment of a program but is not coupled with a comprehensive ABA program (Perry & Longenecker, 2007). In a comprehensive, well run ABA program DTT is only used to teach single units of behavior while incidental teaching or task analysis and prompting are used to teach more complex sequential behaviors in a more natural situation (Perry & Longenecker, 2007). The concerns of autistic individuals (Dawson, 2004) and parents (Fitzpatrick, 2009) who have spoken out regarding ABA have made it known that ABA has variable results and that regulations to ensure ethical practice are essential.

To clarify best practice, The National Research Council (2001) listed several characteristics of an effective intervention for young children with ASD. They indicated that effective programs have the following characteristics: early intervention, intensive instructional programming (5 days, 25 hrs./wk., 12 months), systematic instruction, one on one or small

groups, has objectives addressing social, cognitive, communication, adaptive living, recreation-leisure, academic skill, ongoing monitoring of effectiveness, emphasis on generalization, and opportunities for supported interactions with typically developing students. These guidelines have spurred efforts to provide programs that meet these characteristics.

Howard, Sparkman, Cohen, Green and Stanislaw (2005) compared comprehensive intensive treatments. One was Intensive Behavioral Therapy (IBT) that included discrete trial training, incidental teaching and other ABA techniques. The other condition was an Autism Educational Program for the same amount of time and it used discrete trial training, picture exchange, Sensory Integration Therapy, TEACCH activities, school activities, and speech therapy 1-2 times a week. The result of the study was that after 14 months the IBT program showed significantly greater improvements in intellectual functioning, communication skills, and adaptive behavior compared to the educational program which made smaller gains and some loss of skills. Additionally, the IBT matched the rate of growth of one year of development for children of that age group and their receptive and expressive language improved from well below average to above normal versus the educational group that stayed well below average (Howard, et.al, 2005). Studies on early intervention (children under five years) with Intensive Behavioral Therapy (ABA) indicate that children with ASD who received IBT developed cognitive functioning, language skills and academic performance that approached or exceeded typically developing peers (Howard, 2005).

Results such as these are impressive but research indicates that ABA programs seem to be effective in this way for only 40- 50% of children with ASD, while the other children in the studies had smaller gains in functioning and research has not yet indicated which children are the best candidates for ABA programs (Perry & Condillac, 2003). Additionally, there has been some diversity in how ABA is applied with more recent models becoming integrative (not just the theory of Behaviorism), such as the Early Start Denver Model (Dawson, Rogers, Munson, Smith, Winter, Greenson, Donaldson & Valery, 2010). The Early Start Denver Model integrates a developmental relationship based approach with applied behavioral analysis; as a result, it differs from how ABA was used in earlier studies (affective rich relationship based context with ABA teaching strategies), yet is also showing significant results of improvement in children with

autism (Dawson, Rogers et.al, 2010). Comparative studies of the differences in ABA approaches still need to be explored. Thus, there has been diversity in ASD intervention.

To make sense of the diverse research findings in the area of ASD interventions, pediatric neurologist Martha Hebert (2005) asserted that treatment should be responsive to the heterogeneity of the autism spectrum. Specifically, she indicated that there may be a different emphasis for treatment depending on symptoms and that associated symptoms beyond the three main impairments must be dealt with, such as seizures, gastrointestinal and immune system issues (inflammation of tissue) (Herbert, 2005). Herbert (2005) postulated that ABA may be most appropriate for those *without* chronic physiological issues, while others may need a medical intervention to improve the impact of the behavioral intervention. This position is similar to Ontario, Canada's Best Practices for Children and Adolescents with Autism Spectrum Disorders when they cite The National Institute of Health State of the Science in Autism's position of – "individualized, comprehensive educational behavioral intervention should be the primary approach for all children with Autism, supplemented by a developmental approach, medical approach and others as needed." (Perry & Condillac, 2003, p.69).

What is a parent to make of all these competing views? Because parents may be confused by or not have appropriate services available, or may not be seeing much progress from treatment, it is not surprising that they may look for other treatments. With the internet a wide array of information is available to influence a parent's viewpoint as they journey with their child affected by Autism.

Although parents of children with learning disabilities and AD/HD do not face the same challenges as a parent of a child with classical autism, they share the same process of finding resources and making decisions on how to best support their child. Schools provide various remediation, compensatory and instructional interventions for AD/HD and LD students (Mamen, 2007; Thompson, 1989 and Telzrow & Bonar, 2002). These have included phonological awareness instruction and multisensory specialized instruction for language based LD; problem solving strategy instruction and social skills training for non-verbal LD; and behavior management and parent training for AD/HD (D'Amato, Fletcher-Janzen & Reynolds, 2005). Depending on the effectiveness of or the amount of resources available at the school, parents may have to seek community resources for assessment and interventions. Remediating and

accommodating a LD can be a process of persistence and slow progress (Mamen, 2007), as a result parents may search beyond the school to seek more effective treatments.

Also, parents of children with AD/HD often must decide if they will put their child on medication for AD/HD. Although research has indicated that psycho-stimulants help with the three core symptoms of AD/HD (Charach, Ickowicz, & Schachan, 2004); many parents are reluctant to give them to their children, due to side effects such as growth suppression, decreased appetite, insomnia, headaches, abdominal pain, mood changes and an increase in tics (Selikowitz, 2004), increase in compulsive behaviour (National Institute of Health, 1998), FDA warnings related to cardiac effects (Walraich, 2006), lack of long term safety studies (Schachter, Pham, King, Langford & Moher, 2001) and the necessity of psychosocial interventions to address needs not met by medication (Murphy, 2005). As a result of these concerns some parents have sought alternative methods to assist their child.

The common theme is that concerned parents arrange and advocate for appropriate interventions for their children and in some cases the standard recommended interventions are not always the best fit or satisfactory. As a result, a program such as Brain Balance has had appeal to parents looking for a more effective intervention or an intervention they are more comfortable with implementing.

2.3 Parental Context

Parents of children with neurobehavioral disorders have many experiences in common, even when the impairments of their children may differ. Research describing experiences of these parents has included descriptions of grief, managing stigma, parenting stress, coping with their child's needs (implementing treatment, adaptation in the family), and advocating in the community (accessing treatment, working with service providers/schools, transitions in adolescence, adulthood). Parents of children with exceptionalities, to some degree, share these experiences but the specifics of their experiences will be determined by the characteristics of the child, their own resources and the effectiveness of supports accessed (Perry & Condillac, 2003, 2003). Being aware of these areas of parental experience can assist in understanding parent's reactions to Brain Balance.

Increased stress is a reality in many families with children with neurobehavioral disorders. This increase in stress comes from the challenges of caring for a child with exceptional needs. Diagnosis of their child can be a very challenging time for parents, which can cause feelings of shock, loss and grief (Bourke-Taylor, Howie & Low, 2010; Moen, Hall-Lord & Hedelin, 2011). For example, parents of children with AD/HD have described grieving alone as they felt professionals did not adequately address this issue with them (Moen et. al, 2010). In Ireland, parents of children with autism found the diagnostic process confusing and distressing and that they did not feel they had clear advice on how to proceed (Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2009). Likewise, in Canada, parents experienced stress from the difficulty of finding their way through the service system to access resources (Brown, Ouellette-Kuntz, Hunter, Kelley, Cobigo & Lam, 2011). Additional sources of stress can come from financial issues (extra costs for equipment and therapy), or missing out on activities because of lack of respite care and isolation (Bourke-Taylor, et. al, 2010). A recent study found that stress affected families of children with autism in a number of ways, such as: having little time for family activities; lack of spontaneity or flexibility; increased stress in spousal relationship; job related stress (father's had career restrictions, mothers limited ability to maintain employment and pursue outside activities) and giving up certain aspects of family life (vacations) (Rao & Beidel, 2009). Thus, stress is related to neurobehavioral disorders.

The level or degree of stress related to neurobehavioral disorders differs with type of symptoms and disorder. In autism, the level of family stress was related to behavioral difficulties (hyperactivity, demandingness, disturbed mood, aggressive or self-injurious behaviors) not necessarily the level of severity of symptoms on the spectrum (Rao & Beidel, 2009). In cases of nonverbal learning disability level of parental stress was correlated with level of severity of the impairments, while in language based learning disability stress level was the same regardless of differences in severity of symptoms (Antshel & Joseph, 2006). Parents of children with learning disabilities were prone to higher levels of frustration and dissatisfaction because children with learning disabilities were more dependent and had higher levels of externalizing and internalizing behaviors (Antshel & Joseph, 2006). Generally, parents of children with autism were found to have higher levels of stress than parents of other children with intellectual disabilities (Rao & Beidel, 2009; Dabrowska & Pisula, 2010). While parents of children with AD/HD had higher levels of stress than parents of children with learning disabilities, who had higher levels of stress

than parents of typical children (Antshel & Joseph, 2006). To some degree stress is a reality affecting the parents of children with exceptionalities. A more insidious source of stress for these families is stigma.

Individuals with a neurobehavioral disorder and their families must manage stigma related to the disorder. Stigma is a 'mark' indicating that a person is undesirable and deviant (Koro-Ljungberg & Bussing, 2009). Stigma occurs through social processes involving comparison and devaluation where the majority has judgemental attitudes and reactions (Koro-Ljungberg, 2009). Courtesy stigma occurs when both the stigmatized person and his or her intimates are treated as one in a social situation with the results of separation from the majority, status loss and discrimination (Koro-Ljungberg, 2009). Because of this reality parents use different strategies to manage the impacts of stigma. For example, because mothers of children with ADHD often get unsolicited advice, which implies bad parenting or mother blame, mothers will work hard to develop parenting strategies to appear typical (Koro-Ljungberg, 2009). To deal with stigma, parents adopted various strategies such as minimizing the impact of the disorder, compensating with extra support, normalizing behaviors by interacting with families with children with similar problems, avoiding certain social situations, volunteering or advocating in schools and using spirituality for coping (Koro-Ljungberg, 2009). One critical finding is that stigma causes parents the most stress during social interactions and they do not typically have these stressful thoughts without social prompts (Koro-Ljungberg, 2009). In other words, individuals experience stigma in the context of social interactions (these can include interactions with professionals) therefore changes in wider society de-stigmatizing neurobehavioral disorders are vital to reducing the stress of these families.

In addition to stress, parents of children of exceptionality also experience grief and rewards unique to their parenting experience. Expectant parents often have a hoped for child, that is a fantasy of their ideal child (Hugger, 2012). In our society expectant parents often say 'I don't care if it is a boy or a girl as long as it is healthy.' These early expectancies have an impact on a person's expectations of themselves as a parent and their child (Hugger, 2012). All parents must come to terms with their child being a unique individual and with themselves being a less than perfect parent (Hugger, 2012). This minor disillusionment is a normal part of parenting (Hugger, 2012), but for parents of children with exceptionalities they must come to terms with a larger

discrepancy between the child that was hoped for and the one they love and care for. The result is that parents of children with exceptionalities experience some degree of grief from the loss of the ideal child. Parents of children with autism and AD/HD have described going through an initial grief reaction after diagnosis (Bourke-Taylor et.al, 2010; Moen, et. al, 2011). Parents have described diagnosis as being a time of shock, loss and being grief stricken (Bourke-Taylor, et. al, 2010). Diagnosis requires parents to adjust their expectations for their child.

When a parent has a child with exceptionality they often experience a grief reaction called chronic sorrow. Chronic sorrow results when there is a disparity between what is and what was wished for (Teel, 1991; Roos, 2002). A parent can over time be repeatedly (though not continually) triggered by seeing this disparity and as a result feel periodic sadness, anger and guilt. Parents do adjust to having a child with exceptionality but during times of social stigma, developmental transitions in the family or other triggers they can have flashes of feelings that are similar to grief. Chronic sorrow or grief is a normal reaction to loss of function due to disability or to the loss of the hoped for/ideal child (Roos, 2002; Kearney & Griffin, 2001). These reactions should be thought of as occasional or triggered, as parents are not living in constant emotional distress but come to an understanding of the impact of the disability and know their child as "more than her condition" (Perryman, 2005, p. 605)

Parents of children with exceptionalities can work hard caring for their child and enjoying the rewards (Green, 2007). Parents have indicated that there are rewards unique to parenting a child with exceptionality such as strengthening existing relationships, being stronger during adversity, having more courage, new perspectives and knowing what is important, ability to see beyond disability, comfort with people with disability, and extreme joy when child accomplishes something (Green, 2006; Kearney & Griffin, 2001). The tension between chronic sorrow and the rewards of having a child with exceptionality are part of the context of parents seeking interventions for their child. They are trying to make sense of their situation and gain mastery over it (Gillies & Neimeyer, 2006). Parents are compelled to adapt and often become their child's biggest advocate.

One of the most effective ways of adapting to parenting a child with exceptionality is to go through the process of finding and advocating for supports for the child. Parents are often the first to have a sense that something is not right and seek the opinion of a professional to make

sense of their concerns. In the case of learning disabilities it was found that it is often the parent who seeks diagnosis to make the invisible disability visible (Roll- Pettersson & Mattson, 2012). Parents have experienced the lack of diagnosis of a learning disability as resulting in a lack of understanding of learning needs and a lack of appropriate supports (Roll- Pettersson & Mattson, 2012). Parents of children with a learning disability have used various strategies in assisting their child and often advocate at the school regularly to ensure appropriate supports are given. In some cases parents were in the role of ensuring information passed on to new teachers during transitions (Roll- Pettersson & Mattson, 2012). Parents of children with AD/HD also, experienced frustrations in trying to find appropriate supports for their child in the school system due to such things as poor communication, and lack of individual teaching plans (Moen, et. al, 2011). Parents of children with autism have the main burden of care for their children and must act as advocates and service coordinators (Brown, et. al, 2011). There has been variability of autism services offered and quality of services. For autism, because of age restrictions (i.e. intensive preschool but less services for older individuals), cost of private therapy and limited school supports, accessing care has been a challenge for parents of children with autism, in Canada (Brown, et. al, 2011). Families have had unmet needs because they failed to meet eligibility requirements for supports or because their overwhelming need could not be met by the service system (Brown, et. al, 2011).

All parents of children of exceptionalities have to invest a significant amount of time, energy and financial resources in finding, implementing and advocating for supports for their child (Green, 2007). They do so to see the reward of their child's well being and advocacy is a significant way in which parents adapt to their child's needs (Brown, Howcroft & Muthen, 2010). Given that parents were experiencing stress, and difficult emotions, and were in the role of seeking service and advocating it is not surprising that some parents found and considered the use of a program such as Brain Balance.

2.4 Neurological Research

The Brain Balance Program interprets neurobehavioral disorders as coming from a functional disconnection syndrome (Melillo, 2009). Melillo and Leisman (2009) postulated that symptoms of neurobehavioral disorders are the result of a functional disconnection between hemispheres of the cerebral cortex, at the corpus callosum, which result in uneven development

of the brain; therefore they theorized that the best way to improve these symptoms was to facilitate the coordination between the disconnected areas of the brain. They proposed a multimodal approach called the Brain Balance Program which combined sensory motor exercises, dietary changes (possibly with nutritional supplements) and cognitive/academic exercises; these components are directed at increasing right/left hemisphere activity to the level it becomes coherent with the left/right hemisphere (Melillo & Leisman, 2009). They intended for the program to stimulate the 'weak' hemisphere of the brain (Melillo & Leisman, 2009), which they proposed helps the connection to the stronger hemisphere, creating synchronization. They proposed that improved coordination leads to neuroplasticity or specifically the "improvement of the functional and anatomical connectivity of the two hemispheres" (Melillo, 2009, p. 123). Functional disconnection syndrome was hypothesised, by Melillo, to be the impairment that underlies the neurobehavioral disorders that the Brain Balance Program addresses; he described functional disconnection syndrome as being "the result of a communication problem between the left and the right hemisphere of the brain rather than an injury to a specific area" (Melillo, 2009, p 6).

Functional disconnection syndrome in the research literature refers to a concept that came from classical associationistic models of cognitive functioning (Catani & Mesulam, 2008). Functional disconnection syndrome describes a neural phenomenon where higher mental functions are disrupted by the "destruction of conduction pathways that supplied the inputs and outputs of these centers" (Catani & Mesulam, 2008, p.911). These 'centers' refers to the different areas of the association cortex (a relay station integrating information between sensory and motor areas) involved in the task. A thorough history of how functional disconnection syndrome has evolved over the last 40 years, indicates that the concept has moved from a more simplistic understanding, based on the technology of the time, to an expanded current view that views neurological based impairments as involving various dysfunctions in large neural networks more than functional disconnects between two specific areas (Cantani & Ffytche, 2005). Yet, advances in brain imagery have shown weak connectivity between Broca's and Wernicke's areas in aphasia patients that confirms the concept of functional disconnection that was originally proposed in the nineteenth century; that is there was no structural damage to a specific area of the cortex but a functional abnormality or a dysfunctional connection between two areas (Catani & Mesulam, 2008). Understanding how impairments correspond to the functional connectivity of

the brain continues to expand beyond functional disconnection syndrome; yet functional disconnection syndrome can currently be used to conceptualize some impairments in cognitive functioning. The interested reader is referred to discussions of functional disconnection syndrome in relation to alexia (Epelaum, Pinel, Gillard, Delmaire, Perrin, Dupont, Dehaene & Cohen, 2008) Obsessive Compulsive Disorder (Goncalves, Carvalho, Leite, Pocinho, Relvas & Fregni, 2011) and corpus callostomy (Jea, Vachrajani, Widjaja, Nilsson, Raybaud, Shroff & Rutka, 2008). On the other hand, an example of a more complex understanding of connectivity in the brain beyond functional disconnection is demonstrated by neural studies on ASD.

The theory of connectivity in Autism Spectrum Disorders is characterized by local over connectivity in brain regions and long distance under connectivity between brain regions (Anderson, Druzgal, Froehlich, DuBray, Lange, Alexander, Adildskov, Nielsen, Cariello, Copperrider, Bigler & Lainhart, 2010). This is a conceptualization that in part describes a functional disconnection but also advances understanding to include over connectivity and the overgrowth of white matter (Anderson et.al, 2010). Research confirms that in autism, abnormalities in interhemispheric connectivity are common, yet regionally specific and related to symptoms of autism (Anderson et. al, 2010). Other experiments have similarly indicated that autism is a disorder of functional connectivity where brain regions are not working in a coordinated manner rather than stemming from a specific impaired brain structure (Herbert, 2005). In other words, connectivity abnormalities are a reality in autism but go beyond the conceptualization of a functional disconnection syndrome between the two cerebral hemispheres as specified by Melillo (2009). Nonetheless, advances in brain research have led to new understandings about the neurology of neurobehavioral disorders that may lead to related interventions (Menon, 2011).

2.5 Neuroplasticity

The optimism of creating rehabilitative techniques for brain dysfunction is related to discoveries of neuroplasticity. Historically, it was believed that the brain was unchangeable but research has found this to be inaccurate. Neuroplasticity is the ability of the nervous system to change its structure and function throughout life (Miniussi & Vallar, 2011). Neuroplasticity is the process that underlies maturation, learning and memory, adapting to the environment and to recovering function after injury or disease (Miniussi & Vallar, 2011). Brain reorganization takes

place through changes in dendrite spines and axonal sprouting, both of which cause changes at synapses to organize neuronal connectivity (Berlucchi, 2011). Also, nerotrophins are involved in plasticity by modulation of synaptic transmission (Berlucchi, 2011). Neurogenesis (forming of new neurons) occurs in adults, not just in very young brains, in specific areas of the brain such as the hippocampus which is involved in learning (Berlucchi, 2011). These mechanisms, meaning changes in dendrites and axons or the generation of new neurons, are the neural processes of neuroplasticity; but how the brain is stimulated by its environment is what activates the processes which lead to the difference in the brain's organization and function. Enriched environments, physical and cognitive exercise are associated with learning and changes in dendrites and axons. Whereas stress and sensory deprivation are associated with lower activation and growth in dendrite spikes that would be apparent with stimulation (Berlucchi, 2011).

When working with children one must consider that development is orderly and that each point in development is at risk of interference (Anderson, 2003 as cited in D'Amato et al., 2005). The earlier in development that interference occurs " the more the neural development sequence and trajectory can be disturbed; thus, complications that occur earlier are likely to have more profound and more diffuse effects than complications that occur later in life" (D'Amato et al., 2005, p.67). Clearly, early intervention is important. Discoveries of neuroplasticity show that the brain can change when stimulated to do so (Pinel, 2009). D'Amato and colleagues (2005) indicate that research supports the observation that interventions and rehabilitation can affect brain function.

The findings related to how neuroplasticity changes the brain have led to researchers trying to develop interventions to help individuals with cognitive deficits or dysfunction. These interventions are generally known as cognitive rehabilitation. Cognitive rehabilitation can include behavioral, cognitive, and psychotherapeutic interventions which may be combined with non-invasive brain stimulation, computer assisted learning and neuronal precursors (Berlucchi, 2011). It is thought that abnormalities in the connections between applicable neural networks play a role in the symptoms of cognitive and sensorimotor disorders (Miniussi& Vallar). Cognitive rehabilitation aims to target the functional network responsible for a function by stimulating the network and thereby reinforcing or changing synaptic connections (Berlucchi, 2012).

Research on constraint induced therapies used to regain function in a limb after stroke may increase understanding related to cognitive rehabilitation. In stroke rehabilitation a patient can improve the function of the limb with impaired function by restraining the good limb and working on using the dysfunctional limb. Essentially, the "potential recovery of a damaged neuronal system may be suppressed through a disuse process caused by compensation and substitution strategies" (Berlucchi, 2011, p. 573). In other words, if a weak area is not stimulated but compensated for by other behaviors it will lose function; whereas if you stimulate the weak function it can improve. In each case, it must be evaluated if rehabilitation should be to gain functional recovery or if the weakness should be compensated for (Berlucchi, 2011). To make these decisions further research will continue to explore cognitive rehabilitation. Currently, reviews for cognitive rehabilitation for traumatic brain injuries and strokes indicate that there is evidence supporting the effectiveness of various therapies that improve specific cognitive deficits, yet measures need to be taken of functional improvements not just lab task improvements (Cicerone, et.al, 2005). Stuss, (2011) and Miniussi and Vallar (2011) indicated that cognitive rehabilitation holds promise for brain damage (i.e. stroke) and brain dysfunction (i.e. psychiatric disorders) and calls for research into the factors within the client and in the intervention which determine treatment success.

2.6 Related Research on Interventions for Neurobehavioral Disorders

Although many different cognitive rehabilitative interventions have been developed for treatment of processing problems that underlie neurobehavioral disorders (e.g. CogMed for working memory(Klingberg, Fenell, Olesen, Johnson, Gustafsson, Dahlstrom, Gillberg, Forssberg & Westerberg, 2005) and Arrowsmith Program for learning disabilities (Arrowsmith-Young, 2012).); the following reviews some of the literature relevant to aspects of Brain Balance. Research on the different areas of the multimodal program Brain Balance was reviewed to better understand this intervention. These areas include research on the Interactive Metronome, on Sensory Integration Therapy, on dietary changes, on nutricuetical supplementation and on academic remediation.

2.6.1 Interactive Metronome. Interactive Metronome had been offered as part of Brain Balance and research surrounding the Interactive Metronome has findings relevant to impairments related to motor planning, academic achievement, language abilities and cognitive

processes involved in attentional, learning and developmental disorders (Sabado & Fuller, 2008). Interactive Metronome (IM) is a computer-based interactive version of a music metronome, which was developed in 1992 by child psychologist James Cassily (1996), for the purpose of facilitating motor exercises for improving rhythm and timing (Shaffer, Jocokes, Cassily, Greenspan, Tuchman & Stemmer, 2001). IM allows for intensive repetition of specific motor acts to be matched to the metronome beat while receiving auditory and sometimes visual feedback on the timing of the acts.

Interactive Metronome training consists of 12-15 one hour sessions completed over three to five weeks (Taube, McGrew & Keith, 2007). Thirteen different hand and foot movements are done with guidance from an auditory tone heard through headphones. The individual attempts to match his movement to the metronome beat using the guidance given by auditory and visual feedback, which indicates how closely he matched the beat. Through repeated repetitions the individual becomes more accurate. Timing of movements is measured in milliseconds. The equipment used consists of headphones to hear the beat and receive feedback and motion sensing triggers connected to the computer. One trigger is worn like a glove and the other is tapped by the foot on the floor. The repeated exercises are thought to allow the individual to plan, sequence and process information more efficiently (Koomar, Burpee, DeJean, Frick, Kawar & Fisher, 2001).

The theory behind Interactive Metronome grew out of research in cognitive psychology related to temporal processing or the timing of neural processes. The organizing and sequencing of activities relies on an internal sense of timing or rhythm (Koomar et.al, 2001). This internal sense of timing comes from neural mechanisms which underlie the ability to process the order, interval and duration of sensory and motor events (Mauk & Buonomano, 2004). Most sensory stimuli involve both spatial (what sensory neurons are stimulated) and temporal (timing of pattern of stimuli) processing. Temporal processing can be understood as the decoding of temporal information and of the generation of timed motor responses (Mauk & Buonomano, 2004).

Examples of temporal processing can be seen at work in sequences of motor behavior and in speech and language behaviors. Temporal information on the timing of sounds is important to speech and language function and some researchers suspect that deficits in temporal processing produce language deficits (Mauk & Buonomano, 2004). Similarly, movement involves temporal

processing to coordinate the muscles that produce a movement. If timing is off the efficiency or effectiveness of the movement is impacted (Mauk & Buonomano, 2004). Thus, temporal processing is involved in many adaptive behaviors.

Perceptual learning studies such as Karmarkar and Buonomano's (2003) study showed that timing can be fine tuned with experience. Specifically, they have found evidence that: (1) interval discrimination learning specific to the temporal domain generalizes to the spatial domain and (2) interval learning generalizes across modalities (e.g. training on an auditory task transfers to improvement on a motor task that requires rhythm) (Mauk & Buonomano, 2004). It follows that if timing was improved with experience, than interventions may be developed for difficulties in this area.

Many neural structures work together to contribute to temporal processing and timing is involved in many motor and sensory tasks which manifest as complex behaviors. The brain areas involved in timing are also areas associated with various neuropsychological disorders. The brain structures that researchers have found to be associated with timing are the basal ganglia, cerebellum and the right parietal cortex (Mauk & Buonomano, 2004). Interestingly, the basal ganglia is thought to play a role in AD/HD, OCD, and ASD (Freberg, 2010). Also, dysfunction in the cerebellum plays a role in ASD (Freberg, 2010). Additionally, motor coordination difficulties are often associated with AD/HD, Learning Disabilities, ASD, speech & language disabilities (Reiersen, Constantino & Todd, 2008; Piek & Dyck, 2004; Ramus, Pidgeon & Frith, 2003). It is reasonable to suspect that temporal processing dysfunction (the brain areas involved in this process) may play a role in these complex disorders.

Research on Interactive Metronome is ongoing and researchers have examined Interactive Metronome Training through case studies and small scale randomized controlled trials. IM effectiveness was evaluated for a wide range of disorders. IM effectiveness for individuals with AD/HD was assessed in a randomized controlled clinical trial of 56, six to twelve year olds with AD/HD and resulted in significant increases in attention, motor control, language processing and decrease in impulsivity as measured using pre and post standardized or clinical measures (Shaffer et. al, 2001). Leisman (2010) conducted a randomized controlled trial where 94, six to eleven year olds with AD/HD following a course of IM treatment significantly improved their attention. Additionally, a case study followed a nine year old child with AD/HD and signs of

Developmental Coordination Disorder, who received IM therapy and found that his motor skills improved, his cooperativeness increased, his math fluency increased and his handwriting improved (Bartsherer & Dole, 2005).

Not only does Interactive Metronome treatment seem to improve focus and self-regulation but it has shown promise in assisting those with Nonverbal Learning Disability (NLD), expressive language disorders and problems with reading. Koomar and colleagues (2001) found that when a nine year old child with NLD received IM he significantly improved his attention, improved his pragmatic language (taking turns in conversation, and maintenance of a topic of conversation), improved his motor skills and his word retrieval ability. Sabado and Fuller (2008) found that a 13 year-old girl with oral and written expressive language difficulties improved significantly in language areas, speed of processing and reduced her frustration after she received IM treatment.

Multiple studies, using control groups, have looked at IM training on reading abilities. In a study with 86 elementary students aged seven to ten years, IM trained groups showed an improved ability in timing and rhythm, and significant improvement in early reading skills (improvement in phonics, phonological awareness and in fluency of rapid automatic naming) but no increase in reading level (Taube, McGrew & Keith, 2007). Additionally, in a controlled study of IM training on 250 high school students, researchers found a significant increase in broad reading and fluency in IM trained students, as measured by Woodcock Johnson III Tests of Academic Achievement, compared to a control group (Taube, McGrew & Lazarus, 2007).

Interactive Metronome training has also been applied to improve athletic performance and motor functioning after a stroke. Two studies showed that training with IM in golfers resulted in them significantly improving the effectiveness and accuracy of their swings. (Libkuman, 2002; Sommer & Ronnqvist, 2009). More significantly, stroke patients with arm hemiparesis who trained on the IM showed substantial improvement in arm movement and improvements in activities of daily living (Beckelhimer, Dalton, Richter, Hermann & Page, 2011).

Essentially, Interactive Metronome shows some promise in addressing the impairments of multiple disorders or conditions. It shows promise in improving attention, focus, motor coordination, motor control, language processing, reading and math fluency, and the ability to

regulate impulsivity. The underlying neural process of temporal processing may be found to play a role in many of these difficulties and interventions like IM are thought to work by strengthening the efficiency of timing in the brain across neural networks. Thus, it seems possible that IM training in Brain Balance may be a source of improvement for some individuals.

2.6.2 Sensory Integration Therapy. Sensory-motor exercises are offered as a significant part of Brain Balance. The rationale for these exercises is based on the idea that sensory information stimulates the brain and that not getting proper sensory stimulation can lead to sensory integration dysfunction and resulting impairments; therefore sensory motor exercises can be used to overcome these dysfunctions (Melillo, 2009). This rationale parallels the widely used Sensory Integration Therapy as a proposed means to address sensory integration dysfunctions (Miller, Nielsen, Schoen & Brett-Green, 2009). Reviewing research pertaining to Sensory Integration Therapy provides a means for understanding the sensory-motor aspect of Brain Balance.

Sensory Integration Dysfunction (Ayers, 1989 in Miller, Anzalone, Lane, Cermak & Osten, 2007) also more recently known as Sensory Processing Disorder (Miller et. al, 2007) is a condition which includes multiple subtypes, where individuals have impaired responses to, processing of or organization of sensory information in a way that impairs their functioning (Miller, et. al, 2009). For example, they may be over or under responsive to sensory stimuli, they may have difficulty discriminating differences or similarities among stimuli in a specific sensory modality or they may have poor postural or planned movement as a result of sensory problems (Miller et.al, 2007). Sensory Processing Disorder (SPD) is recognized in two diagnostic classification systems and a group of researchers advocated for it to be included in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (Miller, 2012). There is some debate as to whether the symptoms of SPD should lead to a separate diagnosis or if the symptoms are aspects of other disorders, such as ASD (Bryne, 2008). A sensory integration deficit continuum has been suggested – that ranges from mild regulatory disorders to AD/HD, to PDD- NOS, to Asperger syndrome and finally to autism at the severe end of the continuum (Dorfman, 2004 in Bryne, 2008).It is important to note that changes to the DSM-5 will convert the different Pervasive Developmental Disorder diagnosis into the diagnosis of Autism Spectrum Disorder, thus acknowledging a continuum of severity (http://www.dsm5.org). Research has indicated that there are autonomic and central nervous system differences between those with

SPD versus typical individuals (Davis & Gavin, 2007; McIntosh, Miller, Shyu, & Hagerman, 1999). In addition, SPD has been found to overlap with ASD, and can overlap with AD/HD yet in other cases can be distinguished from it (Piek & Dyck, 2004). It seems the trend in many studies is that SPD can exist alone or be co-morbid with other disorders and is heterogeneous in its presentation.

Sensory Integration Therapy was developed to treat SPD and continues to be studied to determine its usefulness. Sensory Integration Therapy (SIT) consists of challenging therapist lead activities that are designed to give specific sensory input (Miller et.al, 2009). Sensory input may come from such activities as swinging, or spinning (vestibular), jumping, pulling, pushing (proprioceptive), deep pressure touch (tactile) and visual, auditory, olfactory or gustatory input (Miller, et.al, 2009). The child is supported by the therapist to produce appropriate responses or behavior during the activities. The therapist is helping the child to achieve a regulated state, sustain attention, control emotions and complete complex motor actions (Miller et. al, 2009). The theory is that through repetition of the sensory activities the brain will change in ways that will allow the processing of sensory stimulation more typically, thus resulting in the child having more effective behaviors in different sensory environments (Miller et.al, 2009). Thus, the premise behind SIT is neuroplasticity – that is creating new neural pathways in response to repetitive, intensive stimulation of that brain region.

Research on the effectiveness of sensory integration based therapies has been inconclusive due to research design flaws; as a result current researchers are attempting to collect more rigorous data (Bryne, 2008). Prior to 2003, 80 studies were reviewed on the effectiveness of SIT but this did not result in reliable evidence to support or deny the effectiveness of the therapy (Miller, Coll, & Schoen, 2007b). These studies were not well designed and lacked many of the features of a well designed study; therefore reliable conclusions could not be drawn. For example, samples of subjects were not homogeneous; interventions were not manualized or lacked the details to replicate, or studies had problems in methodology (lack of random assignment to groups, lack of blinded evaluators, lack of a large enough sample for adequate power to evaluate significance of results) (Bury & Mead, 1998, cited in Miller et. al, 2007b).

As a result of the need for more rigorous research, Miller and colleagues (2007a, 2007b) conducted a pilot study and a pilot randomized controlled trial on the effectiveness of SIT. The

randomized controlled trial consisted of comparing 24 randomly assigned children with sensory modulation disorder (under or over responsive to stimuli). For ten weeks seven children received a manualized version of SIT, while ten children received an activity group to control for alliance and attention effects and seven children were on the waiting list for the control group. The results indicate that on some post measures, such as Goal Attainment Scaling and Cognitive/Social subscale of Leiter-R that the SIT group did significantly better than the two other conditions. Additionally, the SIT group did better than the control group on a measure of attention of the Leiter-R rating scale. Miller and colleagues (2007b) concluded that SIT may be effective in helping with some difficulties for children with Sensory –Modulation Disorder, but caution was advised given that a larger sample will be necessary to draw firmer conclusions. They suggest a larger randomized trial is necessary. To date this type of study is not available in the literature.

Other recent reviews indicate that the effectiveness of SIT shows a positive trend for results but that overall the SIT's effectiveness is inconclusive. May-Benson and Koomar (2010) conducted a review of the 27 studies conducted between 1979 and 2007 on the effectiveness of SIT, and were unable to provide a firm conclusion about the effectiveness of SIT. The broad conclusion that they reached was that there is a trend of the SI-approach producing positive results compared to no treatment and in some cases being just as effective as alternative treatments (perceptual-motor approach or tutoring) (May-Benson & Koomar, 2010). Positive results included improvement in motor performance, improvements in sensory processing such as change in nystagmus (eye movement after spinning), improvements in tactile discrimination, decrease in sensory defensiveness and gains in self-identified client goals (May-Benson & Koomar, 2010). May-Benson and Koomar repeat previous cautions of reviewers in drawing firm conclusions because of methodological concerns of many of the studies (except for more recent ones) such as: 14 studies lacked a control group, the heterogeneity of populations studied, variation in frequency of intervention, variation in outcome measures and fidelity of treatment.

Other explanations for positive findings, other than treatment effect, have been suggested. Because of the inconsistencies in results from SIT, some hypothesize that positive effects from SIT may be due to the supportive relationship between child and therapist or be from a change in perspective on the part of the parents as a result of consulting with a therapist and having more positive ways of interpreting their child's behavior (Kaplan, Polatajko, Wilson & Faris, 1993).

Others point out that changes from SIT may be attributed to maturation, expectation of parent or therapist, imposed structure, added attention, practice, demands for compliance or coaching on how to play rather than actual changes in sensory integration (Barnek, 2002). The consistent criticism of SIT is that more rigorous studies need to be conducted and replicated before evidence of SIT's effectiveness can be determined.

Recently, a systematic review of SIT used with individuals with ASD concluded that SIT had no consistent positive effect for the treatment of ASD and that it should not be used in an evidence-based setting (Lang, O'Reily, Healy, Rispoli, Lydon, Streusand, Davis, Kang, Sigafoos, Lancioni, Didden & Giesbers, 2012). Lang and colleagues reviewed 25 studies pertaining to the use of SIT with children with ASD. Fourteen of the studies resulted in no benefit, eight studies had mixed results and three showed positive results but with only suggestive evidence (lacking control groups). Of the positive studies one study could be viewed as more ABA based and lacking treatment fidelity to SIT. The second positive study's result was confounded by concurrent speech therapy that may have contributed to the effect on the dependent variable of social initiation. The third study (Thompson, 2011) provides support for SIT but was difficult to interpret as insufficient detail is given to know if the change was statistically significant. For the studies with mixed results there is no consistent pattern. That is in five studies some subjects improved and others did not in the same condition. While in three studies all subjects improved but on different dependent variables. Thus, there was no consistency between studies or within them. Lang and colleagues caution that SIT has no consistent positive effect for ASD; furthermore they warn that it can be problematic for use for treatment of ASD. They caution that SIT may inadvertently reinforce negative behavior by providing an enjoyable activity and break from 'work', or SIT may satiate the child on potential reinforcers or blur contingencies (Lang, et.al, 2012). Clearly, this caution relates to the theoretical perspective one views negative behavior from and a study comparing a behavioral approach to SIT for the treatment of negative behavior assists in understanding their caution.

Delvin, Healy, Leader and Huges (2011) compared SIT to a behavioral intervention for reducing the rate of challenging behavior (including self-injury) of four children with ASD. Results indicate that the behavioral intervention was more effective in reducing challenging behaviors than SIT. In the SIT condition there was relatively little change between the baseline

condition and the SIT condition. Also, for one subject in the SIT condition challenging behavior increased. Delvin and colleagues (2011) note that their findings are consistent with other similar studies; this implies that SIT has not been established to be effective for treating challenging behavior in ASD. Having said that, Delvin and colleagues (2011) concede that the challenging behaviors in their study were reinforced by environmental events and were not challenging behavior that was reinforced by automatic reinforcement (i.e. behaviors that might have a sensory function). The authors suggest further research could clarify this point.

Given that the effectiveness of SIT for any specific application has not been established many professionals advise caution and the exclusion of SIT from evidence-based practice recommendations (National Autism Center's National Standards Project, 2009; American Academy of Pediatrics, 2012). The American Academy of Pediatrics (2012) advises physicians to inform parents that the research on SIT is limited and inconclusive and to assist parents in taking a cautious approach with SIT by monitoring progress (behavior diaries) and setting performance based, time limited treatment goals.

In conclusion, the evidence for the effectiveness of Sensory Integration Therapy is inconsistent and weak. It may have potential for helping difficulties related to motor function and possibly for some sensory processing issues but further research is needed to establish this. Given this evidence it seems unlikely that the sensory motor based exercises in Brain Balance are likely to produce significant functional improvements in individuals with neurobehavioral disorders.

2.6.3 Diet changes and supplementation. Another area that Brain Balance includes in its multimodal treatment is an evaluation of a child's nutritional status and then responding to nutritional deficits with diet changes and supplementation. Melillo (2009) indicated that many children with neurobehavioral disorders have a dysfunctional digestive system with malabsorption and inefficient digestion. His program advised the parent to discover and eliminate food sensitivities and yeast overgrowth (Candida) and to use supplements to counter deficiencies and optimize functioning (Melillo, 2009). By reviewing research into diet changes such as the gluten-free casein-free diet, elimination diets and the use of supplements in the care or treatment of children with AD/HD or ASD an understanding of the implications of the dietary component of Brain Balance can be achieved.

Elimination diets and supplementation or nutricueticals fall under the category of complementary and alternative medicine (CAM). CAM is a group of diverse medical systems, practices and products that are not considered to be part of conventional medicine (Wong & Smith, 2006). Typically, these strategies have not met the clinical standards of evidence (randomized clinical controlled trials) or the consensus of the biomedical community; yet mainstream medicine expands its therapies based on the empirical research that demonstrates efficacy and safety of therapies including CAM therapies such as therapeutic riding for cerebral palsy (Wong & Smith, 2006). The use of CAM is rising and a survey in the U.S. indicated that in 1997 42% of adults used CAM (Wong & Smith, 2006). Furthermore, parents of children with chronic disorders are most likely to use CAM, especially parents of children with ASD (Wong & Smith, 2006). CAM therapies include alternative medical systems (naturopathic, homeopathic); biological-based therapies (diets, herbals, supplements); manipulative and body-based therapies (chiropractic, sensory integration therapy, massage therapy) and mind-body and psychological therapies (music therapy, spiritual healing) (Wong & Smith, 2006). Surveys estimate that 52 to 95% of children with autism are being treated with CAM therapies (Golnik & Ireland, (2009). These therapies typically include supplements such as a B6 and magnesium combination, vitamin C, various vitamin supplements, essential fatty acids, probiotics, melatonin, modified diets and/or anti-infections; less frequently they may include avoidance of immunization, chelation and secretin (Golnik & Ireland, 2009). Surveys have shown that 50 to 76% of parents described bio-based treatments as being helpful (Golnik & Ireland, 2009). In a survey of 539 physicians, over half encouraged the use of CAM while half discouraged the use of CAM (Golnik & Ireland, 2009). It appears that a subgroup of physicians are addressing CAM use in ASD by discussing CAM with parents, incorporating some forms of biological CAM into care (when it is supported by emerging evidence but still needing further studies) and also discouraging the use of certain forms of CAM (Golnik & Ireland, 2009). The surveyed physicians encouraged the use of multivitamins, essential fatty acids, melatonin (for sleep), and probiotics. They accepted the use of gluten-free casein-free diets, elimination of sugar/preservatives/additives diets, probiotics and essential fatty acids if the family was already using the intervention. Additionally, they discouraged delaying or avoiding immunization, chelation therapy because of serious risk of adverse effects, anti-infectives, and secretin. Fifteen studies on secretin have demonstrated the ineffectiveness of this approach for ASD. The survey also indicated that many physicians lacked

enough knowledge of CAM to inform about secretin, vitamin B 12, chelation or melatonin and wanted additional training in CAM. Interestingly, there is a growth of academic pediatric integrative medicine programs in the U.S. (Golnik & Ireland, 2009). Clearly, CAM strategies appeal to parents of children with chronic developmental disorders.

The popularity of CAM obviously reflects a wider societal trend in healthcare but also, reflects the relevance of biological based interventions for neurobehavioral disorders. Biological based interventions are relevant in AD/HD and ASD because systemic factors can effect neurological functioning (Rossignol & Frye, 2012; Kohlstadt, 2009). In addition, in the case of ASD, pathophysiology is associated with the disorder (Rossignol & Frye, 2012; Kohlstadt, 2009). Cognitive and behavioral symptoms of ASD are thought to come from central nervous system (CNS) dysfunction, yet many medical disciplines study multiple non-CNS physiological abnormalities associated with ASD (Rossignol & Frye, 2012). These include physiological and metabolic systems that are implicated in immune dysregulation and inflammation throughout the body (brain, gastrointestinal tract); impaired detoxification and toxin exposure; redox regulation or oxidative stress; and dysfunction in mitochondria or energy generation in cells (Rossignol & Frye, 2012). Previously, 906 studies on pathophysiology in ASD (most written 2006-2010) were reviewed and the majority of studies indicated strong evidence for an association between physiological abnormalities and ASD (Rossignol & Frye, 2012). Furthermore, many studies reviewed indicated an association between the severity of symptoms of ASD and immune dysregulation (Rossignol & Frye, 2012); while another study found an association between gastrointestinal problems and the severity of ASD (Adams, Johansen, Powel, Quig, & Rubin, 2011). Several studies reported improvements in aspects of ASD when treatments targeted a non-CNS physiological abnormality (Rossignol & Frye, 2012).

For example, gastrointestinal problems associated with ASD are varied and some treat these symptoms with diet changes and supplementation. GI symptoms associated with ASD include constipation, diarrhea, foul-smelling stool, gaseousness, abdominal bloating, abdominal discomfort, changes in normal intestinal microbiota, and decreased digestive enzyme activity (Gondalia, Palombo, Knowles, & Austin, 2010). As well, some GI pathology is associated with immune dysfunction (Whitely, Shattock, Carr, Hooper & Todd, 2010). Adams and colleagues (2010) found that the more severe the GI symptoms the more severe the symptoms of ASD; they

concluded that GI symptoms may contribute to symptoms of autism and at a minimum they are unpleasant and cause frustration, discomfort and possibly contribute to behavioral problems such as self abuse. The American Academy of Pediatrics consensus report on treatment of GI disorders in ASD population, advises doctors that GI dysfunction in non-verbal children with ASD may be expressed by aggression or self- abuse (Buie, Campbell et.al, 2010). They made 23 consensus statements regarding the evaluation, diagnosis and treatment of gastrointestinal disorders in the ASD population. The consensus panel stated that in regards to elimination diets that there may be a sub-group of individual's with ASD who may benefit from these diets (further research needs to clarify this); that those who use diets should have professional nutritional supervision; that until more empirical evidence is available that doctors are not able to make specific recommendations for dietary modifications; and further empirical research will clarify the role of metabolic disorders, adverse or allergy reactions, immune dysregulation and inflammatory changes in the role of the cause of GI disturbance in individuals with ASD (Buie, Campbell et.al, 2010). The research on gut-permeability, the efficacy of dietary restrictions in ASD and micro-flora in the intestine were areas the consensus panel recommended for further research (Buie, Campbell et.al, 2010).

There are a number of theories behind how a gluten free and casein free diet works to effect change in an individual's functioning. There are many reports of individuals having improvements in height and weight, cognition and behavior following a G-F-C-F diet. These changes can be attributed to a number of biological mechanisms, such as: (1) gluten sensitive enteropathy or celiac disease - This is a chronic autoimmune response to gluten which results in the flattening of mucosal villi which are involved in the absorption of nutrients (Whitley, Shattock, Carr, Hooper & Todd, 2010a). (2) Food allergy – This causes an inflammatory reaction that follows the production of antibodies to an environmental material (Whitley et. al, 2010a). (3) Underlying hyper-permeability of various membranes including the GI tract and the resulting passage of biologically-active molecules into the central nervous system (Whitley et.al, 2010a). Alternately, one may consider that none of these mechanisms are involved in the effect of the G-F-C-F diet; in that case, one would attribute any change to a general increase in nutrition, the placebo effect or a reduction in carbohydrates (Whitley et.al, 2010a). To further explore the effects of a G-F-C-F diet some empirical studies have been done.

Two well constructed studies examining the effectiveness of a gluten free casein free diet have generated inconsistent results. Elder, Shanker, Shuster, Theriaque, Burns and Sherrill (2006) conducted a randomized double blind 12 week trial of the effect of a G-F-C-F diet on 15 children with ASD. They found that there was no statistically significant difference between the control group and the treatment group; yet some parents and teachers reported improvements in language, reduction in hyperactivity and a reduction in tantrums (Elder et.al, 2006). Interestingly, the authors were able to control for the placebo effect as eight of the parents were unable to distinguish what diet their child was on. The authors caution that the sample was heterogeneous in age, severity of symptoms and cognitive abilities therefore it is difficult to generalize their findings (Elder et. al, 2006). (It should be noted that this is the study the pediatric consensus statement previously cited used to make a statement about G-F-C-F diets in ASD).

A more recent study came to the opposite conclusion regarding G-F-C-F diets. A randomised controlled single blind study of 72 children with ASD over a period of 24 months, found a significant reduction in autistic behavior after 8 to 12 months on a G-F-C-F diet and further small gains were evident from 8 to 24 months (Whiteley, Haracopos, Knivsberg, Reichelt, Parlar, Jacobsen, Seim, Pedersen, Schondel and Shattock, 2010). The improvements were noted by blinded evaluators using standardized assessment tools for ASD. The improvements related to significant improvements in social interaction abilities, communication and reduction in stereotyped and repetitive behavior and reduction in inattention and hyperactivity (Whiteley, Haracopus et. al, 2010b). The researchers indicated that there was no evidence of celiac disease or allergy but the improvement could possibly be attributed to addressing the toxicological affect of food sensitivities acting on the gastrointestinal tract and immune system (Whiteley, Haracopus et. al, 2010). To reconcile the findings of these two well designed studies, one conclusion could be that a G-F-C-F diet could benefit a subgroup of individuals with ASD but the effects may not be evident until the individual is on the diet for longer than 12 weeks and potentially for at least 8 months; thus, lab measures would be helpful to determine who is likely to respond to this diet.

While further research needs to evaluate who is the most appropriate candidate for diet modification, researchers have also investigated the nutritional adequacy of a G-F-C-F diet. Cornish (2002) evaluated the nutritional quality of a G-F-C-F diet and found no significant difference in energy, protein or micronutrient intake between those on a G-F-C-F diet and a

typical diet. In fact for some the G-F-C-F diet was an improvement because consumption of vegetables and fruit increased. A caution may be in order for some children with ASD on the G-F-C-F diet and that is they may be at risk of inadequate intake of proteins when cow's milk is removed. Some children with ASD already have deficient levels of protein (and amino acid levels) and milk may be one of their few sources of protein; therefore when it is removed this has implications in regards to adequate protein intake (Arnold, Hyman, Mooney & Kirby, 2003). This caution points out the need for evaluation of nutritional deficiencies and guidance from a nutritionist when considering the needs of a child with feeding challenges that contribute to deficiencies. In addition to feeding challenges, parents have found the G-F-C-F diet can cause some implementation difficulties such as: (1) difficulty eating at functions outside of home, (2) difficulty finding acceptable alternatives/lack of variety, (3) increased food preparation and cooking time, (4) child wonders why cannot eat what others eat, (5) cost of diet (commercial gluten-free bread three times price of wheat bread) and (6) difficulty initiating diet change (Cornish, 2002). Thus, it appears that difficulty of the G-F-C-F diet are a result of cultural and economic factors related to what is typically eaten in the wider community and not adverse reactions or the general nutritional adequacy of the diet. Hence, the risks associated with this diet are low and the benefits for some with ASD may be significant. Further research will be helpful in determining who the appropriate ASD candidates are for this diet and how it generates its effect as the effort to modify and maintain ones diet in a culinary culture of wheat and dairy are considerable.

Similarly, diet modification has been investigated for individuals with AD/HD. A review study examining the evidence from thirty-five years of research on diets impacting children with AD/HD found that a trial elimination diet is appropriate for children with the symptoms of AD/HD (Stevens, Kuczek, Burguess, Hurt & Arnold, 2011). Evidence on the removal of artificial food colors (AFC) from the diet of children with symptoms of AD/HD resulted in significant improvement in their symptoms (Stevens, et. al, 2011). Furthermore when these children were given a food challenge with AFC they manifested a return of AD/HD symptoms. Interestingly, children tested in the general population all showed a general increase in hyperactivity when exposed to AFC (Stevens et.al, 2011). The editor of the American Academy of Pediatrics Grand Rounds said "The overall findings of the study are clear and require that even we skeptics, who have long doubted parental claims of the effects of various foods on the behavior of their

children, admit we might have been wrong " (Stevens, et. al, 2011, p.286). The findings on the effects of AFC on children resulted in the government of the United Kingdom imposing this sanction on food manufactures: Starting in 2010, they were required to eliminate the following list of artificial food colorings from food and beverages: sunset yellow, quioline yellow, tartrazine, carmoisine, allura red, ponceau red or list a warning label that states "this dye may have adverse effect on activity and attention of children" (Stevens, et.al, 2011, p.286). In the United States, in 2008, the FDA was unsuccessfully petitioned to ban food dyes from food and beverages by The Center for Science in the Public Interest, with the support of 24 doctors and researchers (Stevens, et. al, 2011). It seems evidence suggests that AFC can be a significant factor in the symptoms of AD/HD for a subgroup of children.

In addition, if a child with AD/HD has a sensitivity to artificial food colorings they often have been found to have sensitivities to common foods such as milk, chocolate, soy, eggs, wheat, corn, legumes, grapes, tomatoes and oranges (Stevens, et. al, 2011). Some individuals with AD/HD benefit from the Feingold Diet (which is avoiding AFC, foods that are salicylate containing and preservatives); reviewed studies show 11-33% of hyperactive children respond with improvements in functioning both at home and school on the Feingold diet (Stevens et. al, 2011). Thirty five years of research indicates that a sub group of children with symptoms of AD/HD benefit from eliminating AFC and certain foods they are sensitive to from their diet (Stevens et. al, 2011). Stevens and colleagues' (2011) review of diet modification for children with AD/HD indicates that it is reasonable to do a trial elimination diet to determine if there is an impact of diet on symptoms of AD/HD.

Beyond special diets to treat neurobehavioral disorders, supplementation with nutricueticals has also been suggested for improving functioning of individuals with ASD and AD/HD. Researchers have found that there are deficiencies of various nutrients in children with neurobehavioral disorders (Buie, Campbell et.al, 2010; Kohlstadt, 2009). For children with ASD laboratory testing has indicated metabolic dysfunction, nutrient insufficiencies and overgrowth of microbials (Kaluzna-Czaplinska, 2011). Testing of children with ASD indicates they have deficiencies or imbalances in essential fatty acids, deficiencies in vitamins and minerals, particularly B vitamins, deficiencies in amino acids (e.g. tryptophan) and imbalances in intestinal flora (Kaluzna-Czaplinska, 2011; Kohlstadt, 2009). Similarly, in the case of AD/HD nutrient

insufficiencies are common (Kohlstadt, 2009). For example, children with AD/HD are often found to be deficient in Essential Fatty Acids (EFA), L-Carnitine (Amino acid with role in fatty acid metabolism and other neural functions), iron, manganese, zinc and magnesium (Kohlstadt, 2009). Kaluzna-Czaplinska (2011) was able to distinguish children with ASD from healthy controls by analysis of urine samples which can be used to screen for metabolic problems and nutritional adequacy. When lab testing shows inadequacy of certain nutrients or of biochemical disorders therapeutic treatments related to digestive function and dietary intervention can be useful (Kaluzna-Czaplinska, 2011; Kohlstadt, 2009). Nutritional supplementation for ASD and AD/HD may include supplementation of probiotics, Essential Fatty Acids, vitamins, minerals and amino acids.

Probiotics have been recommended for helping to balance the micro-flora of the intestine in individuals with ASD. Because gastrointestinal dysfunction is significant in some children with ASD and associated with severity of symptoms (Adams, et. al 2011), researchers are exploring the role micro-flora plays in ASD (Gondalia, Palombo, Knowles & Austin, 2010). For example, overgrowth of Candida and its resulting waste products can affect the immune system (Gondalia et. al, 2010). Additionally, imbalanced micro-flora can play a role in GI dysfunction (Gondalia et. al, 2010). Probiotics are live microorganisms which have health benefits related to their role in improving the microbiologic balance in the intestine (Kaluzna- Czaplinska & Blaszczky, 2011). Probiotics are helpful bacteria that have been found to inhibit the growth of Candida (a pathogenic microorganism when overgrown) (Kaluzna- Czaplinska & Blaszczky, 2011). Some studies are showing that the use of probiotics can be effective in reducing levels of Candida (Kaluzna- Czaplinska & Blaszczky, 2011; Gondalia et. al, 2010), with a recent study of individuals with ASD treated with probiotics resulting in a significant improvement in concentration and following directions (Kaluzna- Czaplinska & Blaszczky, 2011). Gondalia and colleagues (2010) caution that evidence for the use of probiotics to reduce severity of symptoms of ASD is just in preliminary stages and it merits further research; but that at this time evidence is inconsistent therefore routine use of probiotics as a regular intervention in ASD is not necessarily warranted.

Evidence for the effectiveness of Essential Fatty Acid supplementation in both ASD and AD/HD is inconsistent, yet it is possible that treating deficiencies of balanced EFA's could be

beneficial (Ortega, Rodriguez- Rodriguez, & Lopez-Sobaler, 2012; Bent, Bertogilo, & Hendren, 2009). Omega- 3 fatty acids are polysaturated fatty acids that come in three types ALA, DHA, EPA and must be consumed as the body cannot produce them (Bent, et. al, 2009). Neural tissues have a high concentration of DHA and omega- 3s generally have an anti-inflammatory effect (Brent, et. al, 2009). A review of studies on the use of Omega -3 fatty acids for ASD revealed insufficient evidence to determine if supplementing with Omega- 3 is effective in reducing severity of symptoms in ASD (Bent, et.al, 2009). One of the studies reviewed was a small scale randomized controlled study. The results showed a small and non-significant improvement in the treatment group, with a trend to decrease hyperactivity and stereotypic behaviors (Bent, et. al, 2009). The other studies reviewed had weaker methodologies and mixed results. A review of the use of omega-3 fatty acids for AD/HD again revealed inconclusive evidence and the necessity of more rigorous methodologies with baseline fatty acid levels determined (i.e. is there a deficiency and does the study last long enough to assess the impact of overcoming the deficiency) (Ortega, et. al, 2012). Five of the studies reviewed showed a modest improvement in symptoms of attention' yet only in one setting or subgroup and four studies showed no effect of supplementation (Ortega, et. al, 2012). All the studies were randomized and controlled but had small samples and did not determine baseline fatty acid levels. At this stage, further research will have to determine the value of essential fatty acid supplementation in neurobehavioral disorders.

Caution is in order for use of omega-3 in ASD because laboratory testing to determine proper supplementation of balanced essential fatty acids is important for safety reasons. Multiple researchers have found evidence that *some* children with ASD have elevated DHA (omega-3) levels that are linked to toxic exposure and these particular children and adults should not be given DHA supplements, as it could contribute to more neural dysfunction (Kohlstadt, 2009, p.375). Children with ASD often have multiple dysfunctions related to fatty acids and this area of research holds promise for understanding neuroinflammation in ASD and for developing targeted nutritional interventions to address it (Kohlstadt, 2009). Children with ASD may benefit from a proper balance of Omega 3s and Omega 6s, not just supplementing with Omega 3s. Thus, because of deficiencies of some EFA's in ASD supplementation with EFAs that are *targeted t*o an individual's disturbances in biochemistry are important and may play a role in treatment of ASD (Kohlstadt, 2009).

As previously noted, children with neurobehavioral disorders often have specific vitamin and mineral deficiencies; some research exists on the use of B vitamins in treatments of ASD. This treatment relates to the finding that children with neurobehavioral disorders have abnormalities related to amino acids and the process of forming neurotransmitters (Pfiffer, Norton, Nelson & Shott, 1995; Kaluzna-Czaplinska, Michalska & Rynkowski, 2011). Vitamins B6, B12 and folic acid are involved in the metabolic process of forming some neurotransmitters or involved in other metabolic pathways (Pfiffer, et. al, 1995; Kaluzna-Czaplinska, et. al, 2011). Improper diet and poor digestion can therefore influence having the necessary building blocks involved in metabolic processes, thereby having an impact on the severity of symptoms of ASD (Kaluzna-Czaplinska, et. al, 2011). This line of reasoning has resulted in the research of using vitamins in a therapeutic way. A review of 12 studies on B6-magnesium combination reported positive responses by children with ASD (Pfiffer, et. al, 1995). Ten out of twelve studies indicated that there was a modest to marked degree of improvement in autistic type behavior (Pfiffer, et. al, 1995). The reviewed studies had some methodological shortcomings (only 75% had a control group and 50% double blind all had small sample size) therefore further research was recommended. It should be noted that B 6 should not be taken in isolation but should be taken with magnesium. If B6 is taken alone in high doses it causes an adverse affect of neuropathy where a person's motor nerves are affected and ataxia results (This reaction is reversible with proper nutrition) (Gdynia, Muller, Sperfeld, Kuhnlein, Otto, Kassubek & Ludolph, 2008).

More recently two B vitamin studies were conducted and continued the trend of therapeutic findings. A 12 week pilot study that was a double blinded, placebo controlled clinical trial of 30 children with ASD being given methyl B12 injections, resulted in instructive findings (Bertoglio, James, Deprey, Brule & Hendren, 2010). There was no statistically significant difference between the two conditions, yet there was a subgroup of nine responders (30%) who had a clinically significant improvement on a Clinical Global Impression for ASD (Bertoglio, 2010). They concluded that because ASD presentations are heterogeneous group analysis can be misleading and result in overlooking a subgroup of responders (Bertoglio, 2010). The findings do not support Methyl B 12 injections generally helping children with ASD but instead for a subgroup of individuals with ASD Methyl B12 will be helpful in alleviating symptoms of autism (Bertoglio, 2010). A study using homocysteine levels in the urine to differentiate children with

ASD from typical children and to monitor impact of supplementation of folic acid, B 12 and B 6 indicates that (1) Children with ASD have higher homocysteine levels excreted in their urine compared to controls, (2) After supplementation of B 6, B 12 and folic acid the homocysteine levels of ASD children lowered significantly, some to levels comparable with controls, and (3) Supplementation with B 6, B 12 and folic acid combined were superior to supplementation of just one B vitamin (Kaluzna-Czaplinska, et. al, 2011). It seems recent research has the beginnings of possibilities of laboratory tests to confirm a subgroup of children with ASD who may derive therapeutic effects from supplementation of vitamins B6, B12 and magnesium. Further research could illuminate this.

Lastly, supplements using amino acids and cofactors have been studied for effectiveness in cases of AD/HD and ASD. There is evidence that individuals with ASD have disordered neurotransmitter amino acid metabolism (Aldred, Moore, Fitzgerald & Waring, 2003) as a result some researchers have investigated the use of amino acid supplementation as a treatment of ASD. Additionally, AD/HD treatment traditionally has focused on the use of pharmaceuticals that are dopamine and norepinephrine reuptake inhibitors to offset the neural dysfunctions of the individual with AD/HD symptoms. Neurotransmitters do not exist in isolation and it follows that an advanced understanding of biochemistry can allow treatments that attempt to restore and regulate neurotransmitters by providing the amino acid precursors that produce them (Harding, Judah, & Gant, 2003).

For example, a study comparing ten boys with AD/HD treated with Ritalin to ten boys with AD/HD treated with a food supplement (amino acids, vitamins, minerals, probiotics, EFA) resulted in both groups having significant improvements from pre- to post-testing on standardized measures of attention (Intermediate Visual and Auditory Continuous Performance Test) (Harding, Judah, & Gant, 2003). There was no significant difference between level of improvement between the two groups; thus, the effect of the dietary supplement was as efficacious as Ritalin (Harding, Judah, & Gant, 2003). Chronic use of medications in AD/HD have been associated with increases in dopamine and norepinephrine metabolism; this has led some to observe that amino acid supplements can prevent further depletion of neurotransmitters caused by medications (Kohlstadt, 2009).

In the case of amino acid research in ASD, a prepilot study was conducted on ten boys with ASD to investigate the effectiveness of a comprehensive bio-based treatment approach concurrent with the children's regular therapies (speech, behavioral, educational, physical) (Patel & Curtis, 2007). The children were tested prior to and after three to six months of treatment with nutrition supplements (amino acids, vitamins, minerals), chelation, G-F-C-F diet, probiotics, EFA and anti-viral injections. The reported result was significant reductions in autistic behavior, improvements in social skills, motor skills, communication skills, GI symptoms and a reduction in urinary lead levels. It is apparent that there are significant methodological difficulties in interpreting what caused the treatment effect in this study and it indicates a bewildering array of treatments suggested for ASD.

As noted, research on the use of amino acid supplementation sometimes happens in studies examining broader nutritional supplements (Patel & Curtis, 2007) but more recently for a subgroup of individuals with ASD amino acid supplementation may be considered essential. A team of researchers have done some preliminary research that indicates autism presenting with intellectual disability and epilepsy caused by *BCKDK* mutations is potentially treatable with the use of amino acids (Novarino, El-Fishawy, Kayserili, Meguid, Scott, Schroth, Silhavy, Kara, Khalil, Ben-Omran, Ercan-Sencicek, Hashish, Sanders, Gupta, Hashem, Matern, Gabriel, Sweetman, Rahimi, Harris, State, Gleeson1, 2012). This team of researchers have made the discovery of a mutation in gene BCKDK which causes a Mendelian form of autism with intellectual disability, epilepsy and associated low plasma levels of branched chain amino acids (BCAA). Their research has shown that mice with a related mutation respond to amino acid supplementation by recovering from neurological symptoms. The researchers are currently working with the individuals identified to normalize plasma levels of BCAA and to determine the effects on their functioning. The incidence of this form of autism is currently unknown as are the mechanisms of how abnormal brain levels of amino acids contribute to autism (Novarino, et.al, 2012).

This very recent discovery, in the etiology of symptoms in a subgroup of individuals with ASD, is a breakthrough and may lead to more effective treatments for many with ASD. Research on the metabolism of amino acids and nutritional therapy research may become better funded as a result. This line of research is not unique to AD/HD or ASD as nutritional therapies using amino

acids to treat other mental disorders are also being conducted (e.g. depression, schizophrenia, OCD) (Lakham & Vieira, 2008). Although, positive results are associated with the use of amino acids for the treatment of AD/HD and ASD further research is needed to refine this approach. For example, amino acids need to be balanced so that they do not deplete other key neurotransmitters (Kohlstadt, 2009). To be safe, amino acids should not be taken in isolation but be balanced and dosage should be considered to avoid adverse effects (Garlick, 2004). Also, research has yet to investigate the effects of long-term use of amino acids (Garlick, 2004). This is similar to some psychotropic medications, as well (Schacter & Ray, 2001). Thus, amino acid supplementation may be a helpful alternative approach in AD/HD and will likely be essential in some cases of ASD but the question of why these individuals have a dysfunction in amino acid metabolic process, or how to treat the dysfunction with supplementation remains to be investigated more fully.

From this overview of biologically based treatments for neurobehavioral disorders it is apparent that this is a large and diverse area of research that holds promise in increasing understanding and treatment of AD/HD and ASD. The difficult issue is that research has not reached a high enough level of evidence to be decisive about directing affected families in specific treatments. As a result, caution is warranted and risks and benefits must be weighed. The evidence anecdotally and empirically is suggestive of the potential for positive results for some individuals with ASD and AD/HD in relation to diet modification (avoidance of food sensitivities and artificial colors) and nutritional supplementation (probiotics, balance of EFA, certain vitamins and amino acids). In the context of suggestive evidence, seeking the guidance of professionals and using lab testing may provide some direction as to what nutritionally based intervention is relevant to a specific child. Existing evidence from research in this area suggests it is possible that diet and supplementation changes may be a potential source of change in Brain Balance for some individuals.

2.6.4 Academic remediation. Finally, academic assessment and academic exercises were included in Brain Balance to address academic problems. They recommended that to correct academic problems a child needs to do drills in their area of academic weakness (Melillo, 2009). This idea is consistent with the academic remediation approach to improving academic performance. Academic remediation is the process of doing academic activities that directly

exercise deficient skills (Telzrow & Bonar, 2002). Academic remediation is included in an extensive body of research into learning disabilities and special education. Although learning disabilities can impact children academically in reading, mathematics and in written expression; the most common type of academic problem occurs in reading (Sencibaugh, 2007; Fiedorowicz, Benezra, McaDonald, McElgunn, Wilson & Kaplan, 2001). Thus, research on reading interventions was reviewed to understand the impact of academic remediation for academic difficulties.

Students who have reading problems typically have difficulty with word identification (decoding), speed and accuracy of reading (fluency) and ability to understand the meaning of what was read (reading comprehension) (Rathvon, 2004). The cause of the reading difficulty in each area can in turn be due to diverse factors including underlying cognitive processing dysfunctions. For example, difficulties in decoding often are the result of problems with phonological processing (includes: phonological awareness – conscious awareness of sound structure of speech, and phonological memory – ability to represent sound information in sequence in working memory), and to a smaller degree to problems with rapid automatized naming (speed of naming visually presented stimuli) and orthographic processing (the use of printed symbols representing speech sounds for processing oral and written language) (Rathvon, 2004). Problems with fluency often relate to low processing speed, problems with decoding, rapid naming or orthographic processing (Rathvon, 2004). While difficulties with reading comprehension can be due to difficulties with the following: using background knowledge, decoding and word recognition (phonological working memory), vocabulary knowledge, fluency, strategy and metacognitive skills (readers awareness of their own thinking) and ability to identify the type of text (Graham & Bellert, 2004/Wong).

Psychoeducational assessment can help to determine the dysfunction which underlies a reading problem. It is from this understanding that appropriate recommendations can be made for relevant and targeted interventions to support an individual with reading difficulty. A growing body of research is illuminating practices that improve performance in decoding, fluency and reading comprehension. This research describes general conditions and specific methods of remediation for reading difficulties.

The necessary conditions for effective remediation of reading difficulties have become better understood over the past few decades. For reading instruction to be effective for students with learning disabilities research indicates that instruction is to be explicit and visible, that instruction be more intense by being offered in small instructionally homogeneous groups, and that tasks difficulty is controlled and includes instruction in both basic aspects of literacy and meta-cognitive strategies (Denton, Vaughn & Fletcher, 2003). Additionally, there are key instructional components that increase the effectiveness of interventions for students with learning disabilities such as (1) sequencing (break task down, fading prompts), (2) drill, repetition, practice and review, (3) segmentation (breaking target skills into smaller units), (4) directed questioning and responses, (5) using structured materials (6) using supplements to teacher (homework) and (7) strategy cues (reminders to use strategies or multi-steps) (Therrien, Zaman & Banda, 2010). Explicit instruction occurs when a teacher thinks out loud, models and teaches skills and concepts in a clear manner that does not require the student to make inferences (Denton, Vaughn & Fletcher, 2003). Intensity of instruction is increased by reducing group size or by increasing the duration of the intervention (Wanzek & Vaughn, 2008). Clearly, students with learning disabilities benefit greatly from one on one instruction, but some studies have indicated that instruction for students at risk of reading failure do just as well in small well designed groups (two to five students) as they do in one on one tutoring (Elbaum, Vaughn, Hughes & Moody, 2000). More recently, Wanzek and Vaughn (2008) reviewed research that indicates that non-responders to reading interventions make significant gains during one-on-one intervention; yet the same gains were also made by non-responders in a small group of three, while this was not the case in groups of 10. Thus, students with learning disabilities should receive reading intervention either one-on-one or in groups of no more than three. Also, intensity can be increased by lengthening the intervention from 10 weeks to 20 weeks (Wanzek & Vaughn, 2008). Research still needs to investigate further how intensity can be increased by lengthening duration of weeks or increasing the length of sessions (Wanzek & Vaughn, 2008).Additionally, controlling for task difficulty is important as this allows the student to remain motivated; they experience less frustration and more success in their attempts to do a tasks that stretches their range but does not set the bar to high (Denton, Vaughn & Fletcher, 2003). Finally, including instruction in both basic aspects of literacy and meta- cognitive strategies allows instruction to be targeted to student needs and allows the student to learn strategies to grow in independence.

Effective instruction for students with learning disabilities is explicit, intensive and uses key instructional components in the relevant area of reading difficulty – decoding, fluency and comprehension.

Specific interventions for improving word identification or decoding skills are important for many students with learning disabilities. Recently, a synthesis of best practices has revealed that encoding instruction alone or integrated with phonemic awareness instruction significantly improves decoding (word reading) and spelling (Weiser & Mathes, 2011). Decoding is the ability to blend sounds and recognize words, when read (Weiser & Mathes, 2011). While encoding is using one's knowledge of sounds (phonemic awareness) and sound to letter correspondence (phoneme-grapheme correspondence) to convert speech into print (Weiser & Mathes, 2011). Encoding instruction includes explicit instruction in writing words according to their phoneme-grapheme correspondence, to use manipulatives (letter tiles) to build words, and to learn to manipulate phoneme-grapheme relationships to make new words (Weiser & Mathes, 2011). Connectionist's models propose that both phonological and orthographical skills are used in processing and interpreting letters, letter patterns, word parts and whole words (Weiser & Mathes, 2011). Thus, word reading is affected by both phonology and orthography as phonemes are associated with graphemes; also, spelling is improved by associating letters with spoken sound (Weiser & Mathes, 2011). Evidence suggests that encoding and decoding instruction are more powerful together than just decoding (phonemic) instruction and that encoding instruction simultaneously impacts decoding (Weiser & Mathes, 2011). Eleven well designed studies indicate that encoding instruction resulted in greater gains in word reading, fluency, comprehension and spelling than just phonemic/guided reading approaches (Weiser & Mathes, 2011). The essential components of the encoding approach are: explicit instruction in phoneme-grapheme correspondences with manipulation of letters; encoding and writing activities of these phoneme-grapheme relationships; word study; guided practice of manipulating and writing specific sound and word patterns and connecting phonemic awareness and encoding instruction to reading, spelling and writing activities that make print meaningful (Weiser & Mathes, 2011). Students struggling with decoding during reading can improve with direct, explicit instruction that integrates encoding instruction with phonemic awareness instruction.

Reading fluency is also a critical area of intervention and research has illuminated interventions that are effective with students with learning disabilities. Reading fluency is the ability to read with speed, accuracy and proper expression (Therrien, Kirk & Wood-Graves, 2012). Reading fluency is associated with comprehension; that is poor fluency results in poor comprehension (Therrien, Kirk & Wood-Graves, 2012). Early research investigated the use of the neurological impress method (having student and a reading model read simultaneously), which produced no significant gains in reading fluency (Therrien, 2004). More recent research has focused on the use of repeated reading. Repeated reading is the process of having a student re-read a short passage two or more times until a certain level of fluency is reached (Begeny, Krouse, Ross & Mitchell, 2009). Research reviews have shown that repeated reading does significantly increase fluency and has a small effect on comprehension in students with learning disabilities (Therrien, 2004). Therrien (2004) specified key instructional aspects of repeated reading to be (1) reading the passage aloud to an adult, (2) cue to re-read up to three or four times until performance criteria is reached (cue reminds of speed and comprehension) and (3) provide corrective feedback on word errors. Repeated reading has been compared to Listening Passage Preview, which is the student reading silently while a proficient model (teacher) reads the passage. Listening Passage Preview has had mixed results but a recent study has shown it to be as effective as repeated reading for improving fluency when used in small groups of four students (Begeny et. al, 2009). The most recent research on fluency intervention has found that when repeated reading using the essential aspects was compared to non-repeated reading yet still using the essential aspects of fluency reading (cued to read for speed and comprehension, read aloud, corrective feedback on word errors), non-repeated reading practice was just as effective as repeated reading (Therrien, Kirk & Wood-Graves, 2012). Non-repeated reading has the advantage of exposing the student to a wider range of vocabulary and texts, thereby allowing for more practice and expansion of background knowledge (Therrien, Kirk & Wood-Graves, 2012). Thus, to improve reading fluency reading practice with feedback is essential but repeated reading is not necessarily (Therrien, Kirk & Wood-Graves, 2012).

Reading comprehension is a critical area of intervention as understanding of texts is fundamental to progressing as an independent learner. Reading comprehension is the extraction and construction of meaning from texts (Sencibaugh, 2007). Poor readers often have difficulty with reading comprehension because of problems with decoding, fluency and problems with

metacognition (Graham & Bellert, 2004). Metacognition involves planning a cognitive task, self-instruction to complete the task and self-monitoring of how one is carrying out the task (Sencibaugh, 2007). Comprehension strategies that can be taught involve teaching how to make inferences, summarize, predict what will happen next, formulate and answer questions and visualize to improve comprehension (Graham & Bellert, 2004). Reviews of research indicate that students with learning disabilities make significant gains in reading comprehension when strategy instruction to organize read materials is used (Sencibaugh, 2007). For example, the most significant effects came from the use of questioning strategies that involve self-questioning, paragraph restatements and text-structure based strategies (Sencibaugh, 2007). Another research synthesis indicated that readers make gains with comprehension strategy instruction that involved modelling thinking aloud how to self-question and reflect on text during and after reading (Edmonds, Vaughn, Wexler, Reutebuch, Cable, Tackett & Schnakenberg, 2009). Additionally, the use of graphic organizers (tool for organizing information) and calling attention to the nature of the text increases comprehension of expository (information) texts (Edmonds et. al, 2009). The instructional methods that research suggests leads to improvements in reading comprehension are: directed response questioning (teacher directing student to ask answer questions); controlling the difficulty of task; elaboration (additional explanation of concepts); modelling by the teacher of steps; small group instruction and strategy cues (reminders to use strategy steps, think aloud models) (Graham & Bellert, 2004). Reading comprehension of students with learning disabilities can be improved with explicit instruction in comprehension strategies.

Effective practices for the remediation of reading skills are known. Sometimes barriers exist that prevent a student from accessing sufficient research based practices through their school, therefore private tutoring can provide the more intensive conditions for progress. If a child has difficulty with any aspect of reading over time explicit, intensive and targeted instruction can assist in improving their reading skills to some degree. It is reasonable to expect growth in academic skills when quality, intensive instruction is given. If Brain Balance is using relevant academic remediation practices, then individuals with academic difficulties could derive some benefit from this aspect of the intervention.

2.7 Pilot Studies

While research is ongoing in different areas used in Brain Balance, research on the multimodal program called Brain Balance was sparse but included some exploratory initial studies. For example, Melillo and Leisman (2010) have conducted studies that use a treatment they refer to as hemisphere remediation strategies or Hemispheric Integrative Therapy. Their 12 week study on 122 children with AD/HD used their multimodal treatment which included academic training, sensory and motor stimulation, aerobic strength and conditioning and Synchronized Metronome Treatment (SMT). The treatment included 36 one hour sessions over twelve weeks and home exercises for academics and primitive reflexes inhibition exercises. The treatment resulted in 81% of parents reporting on a Brown Attention Deficit Disorder Scale that symptoms of AD/HD were no longer apparent as measured by the scale and post testing using the Wechsler Individual Achievement Tests, Second Edition showed significant increases in academic achievement for all measures except math reasoning (Leisman & Melillo, 2010). Additionally, 87% of subjects showed a significant improvement in rhythmic integrated eye-hand and eye-foot coordination, as measured by progress testing for the SMT. Melillo and Leisman (2010) concluded that this pilot study indicates that a clinical trial is indicated for this non-pharmaceutical treatment for AD/HD.

Another example of the use of Integrative Hemispheric Therapy is related in Pedro and Leisman's (2005) case study of implementing the multimodal hemispheric approach in a case of a 14 year old girl with epileptic aphasia. The different aspects of the treatment included Interactive Metronome (35- one hour sessions), nutritional therapy, visual, vestibular, olfactory, auditory, somatosensory stimulation. The frequency of treatment was 4.5 hours per week for 12 weeks. Pre- and post-testing was conducted for cognitive function, academic achievement, and EEG. After the treatment her EEG was controlled and her auditory processing significantly improved. Additionally, the treatment resulted in improvement on measures of reading, language and behavioural social measures. She was able to unlock doors, button and unbutton clothing, was more expressive of her needs, and consistently listened to and followed directions. These researchers concluded that their multimodal approach deserves further investigation.

In addition, to the center run Brain Balance Program, Robert Melillo (2009) developed an At Home Brain Balance Program, which is based on the functional disconnection hypothesis. It is a

program to assist in the functional improvement of children with neurobehavioral disorders, such as Autism Spectrum Disorders, AD/HD and LD. The program includes a handbook to guide parents in leading their child through sensory motor exercises, academic exercises, a behavioural and nutrition plan (Melillo, 2009). A parent led intervention can be useful when professional resources are limited or in remote areas. For example, Shin, Nhan, Lee, Crittenden, Flory and Hong's (2009) study of a parent applied home based intervention for children with intellectual disabilities, in Vietnam, played an important role in the optimal development of their child and was the best option in areas of Vietnam lacking services. Similarly, Melillo's home-based intervention has the intention of helping children with neurobehavioral disorders, who may otherwise not have access to his approach. Yet, he states that it does not replace or produce the results of the program that can be given from a Brain Balance Center. There is no research on the at home version of Brain Balance.

Research on the multimodal Brain Balance Program is needed to understand and explore this multimodal treatment which is attempting to apply the premise of neuroplasticity to interventions. Because research on Brain Balance was limited (Leisman & Melillo, 2010) a study providing a rich description of parental experiences with the program was a way to begin to explore this controversial program and serve as a needed extension of the research in the application of neuropsychological interventions. The specific research questions guiding the study were: (a) What is it like for parents and children participating in Brain Balance? (b) What are parents' judgements about doing Brain Balance? (c) What are the impacts of Brain Balance on parents and children? (d) What motivates parents to do Brain Balance? and (e) What motivates parents to write about the experience online?

CHAPTER 3: RESEARCH DESIGN

Research design encompasses the underlying framework and processes involved in conducting a study. The following chapter details the paradigmatic assumptions, the methodology, data collection, analysis and ethical considerations behind this study.

3.1 Paradigmatic Assumptions

Paradigms are basic sets of beliefs which guide actions (Denzin & Lincoln, 2005). In the research context, they influence how a researcher examines a phenomenon of interest, influence what a researcher finds interesting, and determine what a researcher thinks she or he might discover. Paradigms are part of the worldview of a researcher and include axiology/ethics, ontology, epistemology and methodology. Research questions are embedded in a paradigm, and as such, awareness of paradigmatic assumptions assists the development of a research project. The current study's question was multifaceted, had dual purposes and was focused on application, which aligns with a pragmatic paradigm.

As I considered the phenomena of Brain Balance, it became apparent that my thinking was evaluative in nature. I wanted to describe and evaluate the program in a way that was useful to interested stakeholders (parents and professional helpers). Therefore, my understanding of what knowledge I hoped to find and how I could find it seemed to borrow from different paradigms. I realized that I take the view of a critical realist, who thinks the world exists without a mind but (the critical part) I also seem to have a constructionist epistemology that states meaning cannot exist without a mind (Crotty, 1998). A constructionist epistemology indicates that knowledge is constructed out of an individual's subjective views or understanding about the world/reality (Caelli, Ray & Mill, 2003). My thinking about existence (ontology), knowledge and how I come to know it (epistemology) causes blurring of paradigms and I end up being pragmatic instead of being anchored in a purer paradigm. Denzin and Lincoln (2005) gave a great discussion about the shifting and blurring of paradigms, throughout qualitative research's history. They indicated, that to many, the methods in pragmatism are a challenge that could shove qualitative research back into a positivist box to be subordinated because it welcomes mixed

methods (Denzin & Lincoln, 2005). On the other hand, Patton (1990) confidently indicates that qualitative research is legitimate and cannot be subordinated in instances where it is the best fit for the problem, at hand. Clearly, he is a pragmatist.

Pragmatism is concerned with applications and solutions to real life problems (Patton, 1990). In pragmatism, knowledge comes out of actions, situations or consequences (Creswell, 2003) and the relationship of the researcher to the subject can vary based on the researcher's intent. Thus, this relationship could be interactive with both researcher and participant co-creating of findings (a constructivist orientation) or the researcher could be manipulating variables and observing (a postpositivist orientation). Hence, pragmatic epistemology is responsive to the research problem and uses pluralistic approaches to know and learn about the problem (Patton, 1990). The nature of reality or ontology of a pragmatic paradigm is that there is a single reality, yet all individuals have their own interpretation of it (Mertens, 2010). Pragmatics recognize that research occurs in social, historical and political contexts; therefore pragmatists are free to use a theoretical lens that considers social justice and political aims (Creswell, 2003). The axiology of pragmatism is reflected in the researcher pursuing desired outcomes that are influenced by their values and politics. As a result, one cannot assume the values or political position of a pragmatist. In this paradigm, there is room for diversity. The values that drive the present study follow the ethical mandate of psychological practice and value the voices of those who are often under- represented in research. In this case, the voices of parents who participated in the intervention were valued.

The pragmatic paradigm allows a descriptive perspective that could contribute to an evaluation of Brain Balance. I asked how Brain Balance works (describe) and what the parent's perceptions of the program are (judgement); thus satisfying some of the questions both parents and clinicians have about this program. Pragmatism allowed me to focus on the problem and gave me the flexibility to choose methods that were consistent with my question and resources. The researcher needs flexibility to use any method that will allow questions to be answered; therefore they may not stay in just a qualitative or just a quantitative orientation (Patton, 2002). Instead they must do what they need to do to obtain useful data. Brain Balance is a complex intervention that is entwined with its context; therefore to fully investigate Brain Balance researchers will have to look at it from multiple perspectives and over time with a mixture of both

quantitative and qualitative methods. A quantitative approach is needed to determine the effectiveness of the program in terms of what variable causes what effect or what aspects of the program lead to functional improvements. In other words a quantitative approach helps determine the outcomes of the program, but a qualitative approach accesses data such as understanding the processes involved in doing the program for families with children in the program and understanding how parent's make sense of their own and their child's experiences connected to the program. This information is important to the understanding and evaluation of Brain Balance because it allows stakeholders to make decisions about the program; it allows a better understanding of what is involved in the program and how this compares to other interventions. Also, the information gained can be used to generate ideas for further research of this phenomena or related phenomena. Ultimately, findings of a qualitative investigation of Brain Balance could stimulate actions that would benefit those with neurobehavioral disorders and expand knowledge in the area of intervention for neurobehavioral disorders.

Denzin and Lincoln (2005) indicated that "qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (p. 3). Thus, the main aim of qualitative research is to understand how people make sense of their experiences or lives (Merriam, 2009). This aim fit well with my research question, which is to understand the experiences of parents with children in Brain Balance. By understanding their experiences, stakeholders can better evaluate Brain Balance. These understandings can (a) contribute to innovation in this program or other related ones; (b) better inform decision making for those unfamiliar with the program; and (c) stimulate further research and development into interventions for individuals with neurobehavioral disorders. By producing a description of parental perceptions and experiences of the program, this study could contribute to the evaluation of Brain Balance by using a descriptive qualitative approach.

3.2 Methodology

Basic qualitative descriptive methodology (Merriam, 2009, Sandelowski, 2000), used with the purpose of generating descriptive findings that has nuances of evaluation was a suitable qualitative methodology to systematically investigate parental experiences with the Brain Balance Program. A basic qualitative descriptive study is a methodology that fit in my paradigm assumptions and assisted in answering my research question.

Basic qualitative descriptive research has constructionism as its foundational philosophy and draws on natural inquiry. Hence, rather than the meaning of the phenomena being found, meaning is constructed or built as participants interact with the phenomenon (Crotty, 1998). In this methodology, the researcher is trying to understand the meaning a phenomenon has for the participants or the meaning they have constructed as they interacted with the phenomena (Merriam, 2009). In addition, to allow natural inquiry the researcher studies the phenomena in its natural state as much as possible. Thus, no variables are manipulated nor are any prior theoretical views of the phenomena held (Sandelowski, 2000). By using online documents parents have spontaneously produced while interacting with the program, I viewed parental meaning making that happened and was documented naturally without interference or guidance from an observer.

In basic qualitative description a summary of the phenomena is given in the everyday terms of the phenomena with the goal of describing the meanings individuals attribute to events (Merriam, 2009; Sandelowski, 2000). The researcher is "interested in understanding how people interpret their experience, how they construct their worlds and what meaning they attribute to their experiences" (Merriam, 2009, p. 5). The description of the phenomena should have descriptive validity (a depiction of events that most would agree is accurate) and interpretative validity (a depiction of participants meanings that those participants would agree is accurate) (Sandelowski, 2000). In the case of Brain Balance, I described parent's experiences with this program and their interpretations of the program; the process of their child going through the program, their judgements about the program and the meaning of writing about the experience.

Anytime a judgement is made a person is engaged in evaluation (Patton, 2002). In this sense, asking questions regarding parental judgements and reporting these judgements about Brain Balance gave this study an overtone of evaluation; yet the study was not actual evaluation research. Evaluative research is the process of using quantitative methods or qualitative methods or both to make judgements about aspects of a program (Borg, Gall & Gall, 2010). Furthermore, evaluation research systematically studies the processes and outcomes of attempted solutions to societal problems (Patton, 1990). This study does not explicitly by design or findings fully achieve an evaluation. Instead of evaluation research, the main methodology of the study was basic qualitative descriptive research with overtones of evaluation that may contribute to an evaluation. The overtone of evaluation comes from the questions asked, my analysis and the

parents' judgements about the process of doing the program and judgements about the outcome of the program. Thus, a part of the parents' meaning making of Brain Balance included themes of evaluation and as part of the end product of the study these evaluations/parental judgements were described.

A basic qualitative descriptive study provided the means to answer the research questions and a description was produced. This research design allowed for thick description, which in turn, revealed the parent's natural interpretation of the program in process. A basic qualitative descriptive study helped to illuminate the process experienced by a parent and child doing the program; described what judgements the parent made about the program and described the motivation for publicly writing about the experience. Ultimately, this methodology allowed the purpose of the study to be achieved.

3.3 Methods

3.3.1 Data sources. The phenomena studied was parental experiences of Brain Balance, as described in online documents by parents who have children with a neurobehavioral disorder, such as ADHD or ASD. The study included a sample of online documents written by parents. Sampling is the method used to choose a certain number of people or things from a population (Mertens, 2010).

Purposeful sampling was used to find online parent authored documents. Purposeful sampling allows for finding information-rich cases, whose study will illuminate the questions being considered (Patton, 2002). The strategy that was used to get a purposeful sample was criterion sampling with maximum variation. Maximum variation involved reviewing all cases that met predetermined criteria of importance and selecting cases that demonstrate variations of the phenomena (Patton, 2002). For example, some documents vary in the type of impairment the child has or in the parent's point of view of the intervention. By allowing a heterogeneous sample, "common patterns that emerge from great variation are of particular interest and value in capturing core experiences and central shared dimensions of a setting or phenomena" (Patton, 2002, p. 234). The goal of sampling was to seek information rich cases that meet criteria that fit the study's purpose of describing the program from parents' perspectives and allowing parents of children with neurobehavioral disorders to share their judgements about Brain Balance. The online documents met the following criteria in order to be included:

- A first-hand account written by a parent of a child with a neurobehavioral disorder;
- A publically accessible online document written in the last four years (2009-2012)
- Pertains to Brain Balance.

To allow for maximum variation, I was looking for postings critical of Brain Balance (some based on experience with the program and some experience with the advertising) and postings that shared the experience of doing the program (some generally positive and others some degree of progress). I read through online postings scanning for who wrote it and whether it was a critical, positive or in between posting. I then looked for details of how they were involved in the program and the timeline of their involvement. Additionally, I considered the quality of writing, the amount of detail and the frequency of posting. I also considered the diagnosis of the child (was it relevant to who the Brain Balance program is marketed to).

Online postings from parents that shared stories of improvement were more numerous than online postings that were critical of Brain Balance. No complaints were found regarding Brain Balance Centers in an online search using the term Better Business Bureau Brain Balance Center, at the time of this study. Nonetheless, some critical postings were found written by parents in other online formats. Out of seven specifically critical online postings from parents three were chosen for the study. Out of 24 independent online blogs written by parents documenting their Brain Balance experience three were chosen. While there were other postings online regarding Brain Balance, they were excluded from the sample because they were not written by a parent but were written by various other individuals debating aspects of Brain Balance theory or because they were parental testimonials that were posted on a Brain Balance Center website.

Documents that are first-hand accounts written by parents allow the parental voice to be heard on this intervention. This voice includes a range of views. By ensuring that the documents were public the analysis could proceed without getting consent from the parents and without interacting with them. In this way parental statements occurred naturally, spontaneously and were not influenced by my presence. Looking for documents in the last four years situates the study in a specific historical context. This is the time period that occurs after Melillo published his book

on his program. Focusing on documents about Brain Balance rather than other interventions allowed the focus of the study to be narrowed.

Specific documents were found by searching for blogs or other online postings about parental experiences with Brain Balance. Various search engines were used to search for blogs, including Google, Metacrawler and Dogpile. Once specific blogs and other relevant postings were located they were evaluated to see if they meet the inclusion criteria. The sample of documents was chosen from the collection of online parent documents about Brain Balance available between September 2011 to November 2012.

I conducted four different searches for data over the period from May 2012 to November 27, 2012. I did searches on September 1, 2011, May 22, 2012, September 5, 2012, and November, 23, 2012.The final list was the result of these four different search times. I reached saturation by finding the same postings on a number of different times and a number of different search engines or some that were only on a certain search engine. I searched using multiple terms and kept looking on search result pages up to page 14 or until the search terms were no longer showing with the original meaning (i.e. brain balance becomes split into "for balance ..... The brain is ....vs. Brain Balance is a program....).Of the online documents that met inclusion criteria, a smaller number were chosen to allow for maximum variation.

3.3.2 Online data collection. Using the Internet as a tool for research and a source of participant's data resulted from issues of feasibility, geographic distance of the potential participants and consideration of methodological consistency (Prior, 2004). The use of Internet documents to study parental experiences of Brain Balance made it feasible to access stories from parents that were at a considerable geographic distance. Brain Balance was available in various centers spread around the United States and a Canadian researcher would not be able to easily conduct research at the locations of the participants. The use of internet documents allowed the researcher to include authors from various geographic locations. Also, the postings on the internet regarding Brain Balance allowed a pool of individuals who were involved in Brain Balance to be found without contacting the Brain Balance Centers directly or advertising in various cities. In this way, the researcher had a feasible way of finding cases with some variation rather than being limited by the cost of advertising or only finding those referred by the center. Given practical and feasibility issues, the use of online documents made this study possible.

Additionally, some methodological considerations fit well with the use of online documents about Brain Balance. For example, basic qualitative descriptive research is concerned with conveying the description of a phenomenon in the everyday language of that phenomenon (Sandelowski, 2000). Using online documents as a data source allowed the views of parents to be viewed in their unsolicited everyday language. Also, in a basic qualitative descriptive study it is important to study the phenomena in its natural state and to use tools that will allow the phenomena to be seen as if it were not under study (Sandelowski, 2000). Furthermore, the phenomena is studied inductively, the researcher does not pre-select variables to study, does not manipulate variables and has no prior theoretical view of the phenomena (Mertens, 2010; Sandelowski, 2000). Instead the researcher 'observes' the specific phenomena and lets categories or findings emerge from the data (Mertens, 2010). Using online documents to 'observe' parents experiences of Brain Balance allowed their statements to happen in a natural way that was not influenced by the researcher's design of the study (Merriam, 2009). These documents existed and were produced without the researcher soliciting any response; but instead had been motivated by the parents' wanting to communicate about their experiences with the phenomena of interest – that is the documents are grounded in the real world and are independent of the research agenda, therefore not influenced by the researcher (Merriam, 2009). The parents voluntarily made a public statement about their experiences by writing documents online. They expressed themselves in their current context and often their purpose of communicating online was compatible with the research question – understanding parent's experiences and judgements about Brain Balance. In this way the online documents about Brain Balance were an information rich source to start investigating the research question.

Online documents are a way for researchers to use familiar techniques in a way that enlarges their sources of data. Documents can be used to gain descriptive information, discover new categories and hypotheses and track development (Merriam, 2009). Generally, documents can be analysed for information from primary sources. Primary sources give firsthand accounts of the phenomena. In this case the internet Weblogs and web forums were parents' reflections on their perceptions of Brain Balance as they support their child through the program. Weblogs or blogs are a website that is self-published and updated regularly (Silva, Mousavidin & Goel, 2006). The content of a weblog is typically text but can include pictures and video. The contents are archived in reverse chronological order and can allow visitors to post comments. The subject

matter is often in the style of a personal journal, reflections or comments and centers on a central theme or topic/purpose. Besides blogs, web forums were used as a source of documents. Web forums are also called message boards, online forums or web bulletin boards (Dochartaigh, 2002). A web forum is often attached to a website about a specific topic; therefore the web forum is usually a discussion related to the website. Anyone can connect to a forum, read messages or post messages. Some forums have a moderator to monitor them and some allow postings from only registered users. These forums have more structure to avoid abuses or misuses (advertising); hence a moderator can block a comment from being published (Dochartaigh, 2002). Both blogs and web forums provide a way for like-minded people to interact and communicate about a shared interest. Both allow information to be publically voiced and for others to interact at their convenience. They are an outlet for people to share their views. Also, they do not require advanced technical skills and are available to anyone with access to the internet. The online documents of this study were a rich source of data.

The online documents of this study included three blogs in entirety, a specific posting from a large blog of many years and two postings from web forums. The three large blogs had postings that were entered over the entire period the child was in the program while the other shorter postings were more summary in nature. The three larger blogs were high in detail, while the shorter postings had specific relevant comments. The amount of data accessed from these six different parents was rich enough to identify themes that were common to their experiences but also had enough variation to see unique viewpoints depending on the symptoms of their child or family situation. By choosing these postings I attempted to give a balanced view of the online parental postings on Brain Balance during a time period (September 2011-November 23, 2012).

An online document can be treated in the same manner as an off-line document. Merriam (2009) indicated that researchers must locate documents, verify their authenticity and copy and catalog them. Locating documents requires a researcher to be resourceful and an online search raises some unique issues.

Using documents on the internet required careful procedures to copy them. Due to the nature of the internet, information can change or disappear; therefore the document may not be in a stable form (Merriam, 2009). Steps were taken to copy the documents so that they remained

intact for analysis. There was a paper copy and a digital copy produced. Periodic checking of the online site was necessary to ensure the document was complete during the analysis.

When using documents the authenticity of the document needs to be considered to increase the trustworthiness of the data. A researcher must reflect on the origins of the document, the reasons it is being written and the context in which it is written (Merriam, 2009). Merriam (2009), citing Clark (1967), provides a list of questions that could be asked to evaluate the authenticity of a document:

> What is the history of the document? What guarantee is there that it is what it pretends to be? If the document is genuine, under what circumstances and for what purpose was it produced? Who is the author? For whom was the document intended? Does the document represent an eyewitness account, a second hand account, a reconstruction of a past event, an interpretation? What is the maker's bias/ to what extent is the writer likely to tell the truth? (pg.151)

A researcher must keep in mind that personal documents are subjective accounts that are interpretations subject to the writer's memory and biases (Merriam, 2009). Nonetheless, the information from primary documents was an excellent source of data of parental experiences of Brain Balance. I confirmed the center the blog referred to and inferred many of these other questions of authenticity from the content of the blog.

3.3.3 Analysis. In basic qualitative descriptive studies data collection occurs simultaneously with analysis and researcher reflexivity. The reason for this union of processes is that the researcher is the instrument of both endeavours and one process informs the others. In qualitative research the design is emergent, meaning that the analysis of the data can lead to new understandings that require new or refinement of questions and direct further data collection and the refinement of analysis. Analysis in descriptive studies is understood to be recursive, that is interpretations are reconsidered and come back to in the analysis (Merriam, 2009; Mertens, 2010). Also, analysis of data informs what other data to collect. Additionally, data collection begins with initial analysis of what the researcher already understands about the phenomena. Qualitative descriptive studies acknowledge the disciplinary and practical knowledge that a researcher brings to a study (Hunt, 2009; Thorne, Kirkham & MacDonald-Emes, 1997). In this case I had prior practical and disciplinary knowledge of interventions for the treatment of neurobehavioral disorders. This knowledge was what raised my interest in the study of parents'

experiences of Brain Balance. In qualitative descriptive studies this subjectivity is valued in that as the instrument of data collection and analysis a researcher's "subjectivity can be seen as virtuous, for it is the basis of researchers making a distinctive contribution, one that results from the unique configuration of their personal qualities joined to the data they have collected" (Peshkin, 1988. p. 18). Yet, a researcher needs to manage their subjectivity so that the emic or participant's perspective can be heard (Peshkin, 1988). The researcher needs to always consider their impact on the data collection and interpretations (Mertens, 2010). Ultimately, data analysis in basic qualitative research is concerned with generating findings which increase understanding of a phenomenon, a process or how people make sense of their experiences – it reflects the emic point of view (Merriam, 2009). I strived to allow the emic perspective to be seen by providing quotes directly from the parents writing.

To increase understanding of parent's experiences of Brain Balance a reflexive analysis of the data was undertaken. Borg and associates (2010) relate that reflexive analysis is the process of a researcher using her own intuition and judgement to analyze data. The reflexive approach that is used in basic qualitative descriptive studies is conventional qualitative content analysis. Conventional qualitative content analysis is a way of making sense of the verbal and visual data by summarizing the informational contents of the data (Sandelowski, 2000). Conventional content analysis is "a research method for the subjective interpretation of the content of text data through systematic classification process of coding and identifying themes or patterns" (Hsieh & Shannon, 2005, p. 1278). The aim of conventional content analysis is to describe a phenomenon; thus this was the form of analysis used in this study.

The processes involved in content analysis generally are immersion in data, inductively forming categories and reduction of categories into broader categories and relationships (Hsieh & Shannon, 2005). To be immersed in the data the researcher begins by reading the full text to get a sense of the whole. Getting a sense about who is telling, where is it happening, when did it happen, what is happening and why; are questions that allow grasping this sense of the whole (Elo & Kyngas, 2008). The inductive forming of categories starts with open coding. This can be headings in the text while rereading it. The code comes from the data in terms of main concepts or thoughts that relate to the research question. At this point the researcher makes notes on her initial impressions, thoughts and initial interpretations. The process of reduction occurs when

initial codes are organized into categories based on how codes relate and link. This process involves a reflection on meaning (Merriam, 2009). Then categories are refined into meaningful clusters. Sometimes a diagram is used to organize categories into hierarchical structure. Definitions for each category, subcategory and code are made and examples in the text are identified. Categories are patterns or themes expressed directly in the text or through analysis are derived from the text (Hsieh & Shannon, 2005). A system for organizing the coding and categories was necessary to retrieve units of data and to work with it (Merriam, 2008). This system consisted of colors for the research question the theme fit, letters and numbers to identify the portion of the document and words describing the theme. The result of content analysis is a description of the phenomena through categories/themes that describe the data (Elo & Kyngas, 2008).

Another crucial part of the process of analysis is procedures that facilitate researcher reflexivity. The reflexive procedure used in this study was the use of memos. Memos are a research technique that allows a record of the research journey and illuminates a researcher's subjective perspective interacting with the data (Birks et.al, 2008). Birks and associates (2008) assert that memos function in various ways to increase trustworthiness of the study. Memos recorded the decision making process during the study (audit trail), activities conducted and the rationale for their use. Memos facilitated the analysis of data by being a place to contemplate interpretations. Also, memos helped record the perspective of the researcher, thereby sharing one of the contexts of the study. A memo was created by writing a notation in a journal. It was dated, and cross referenced to relevant data. Peshkin (1988) indicates that memos should be written as a way of observing the self when one has a feeling a reaction to data. "Look for the warm or cool spots, the emergence of positive or negative feelings, the experiences I wanted more of or wanted to avoid and when I felt moved to act in roles beyond those necessary to fulfill my research needs"(Peshkin, 1988, p. 18). By using memos I have managed my subjectivity and tell "where self and subject become joined" (Peshkin, 1988, p. 17). Managing my subjectivity facilitated making sense of the data in a way that is credible.

Through reflexivity and content analysis the participant's views interacted with mine in a transactional process to help understand their experience of the program (Patton, 2002). A basic qualitative descriptive approach with nuances of evaluation allows readers to become informed of

an understanding and description of parents' experience and evaluation of Brain Balance. Thus, the result of my analysis is a descriptive summary of parents' experiences with Brain Balance that includes their evaluation of the program.

3.3.4 Trustworthiness of findings. A basic general descriptive study suggests the use of specific methods that will allow the research questions to be answered in a way that increases the credibility/validity, dependability/reliability, confirmability and transferability of the findings (Marshall & Rossman, 2011; Merriam, 2009). For a qualitative study to be trustworthy it must be credible and dependable. Credibility relates to having the study's findings correspond to the real world or to accurately depict the data collected (Merriam, 2009). Dependability occurs when the findings are consistent with the data collected (Merriam, 2009). In qualitative research if a study is replicated the findings are not expected to be exactly the same but to be consistent with the data collected at that specific time. The reason being is that no variables are controlled and human behavior is not static so exact replication is not possible (Merriam, 2009). Additionally, a study can increase its relevance by using strategies to increase transferability of the findings. The reader of a study determines transferability from description provided by the study (Mertens, 2010). Essentially, that reader decides if the findings are applicable to her situation.

Research procedures used in this study to increase trustworthiness were peer review, thick description, an audit trail and reflexivity. Peer review was used by having a supervisor review findings to ensure they were rooted in data (Marshall & Rossman, 2011). This peer review was done repeatedly and contributes to the credibility and dependability of the study. Thick description in describing the setting, relevant characteristics of the participants and detailed description of the findings with evidence in the form of quotes from documents has been provided so as to allow readers to determine the transferability of the findings. The reader will be able to decide from the description if the findings are applicable to their situation (Merriam, 2009). Also, an audit trail was provided in the form of an account of how the study was conducted and how the data was analyzed (Merriam, 2009). The audit trail consists of memos where there is a description of how data was collected, how categories were made and how decisions were made during the study (Merriam, 2009; Birks, Chapman & Francis, 2008). Through the audit trail the logic of the study can be understood by being presented with a chain of evidence that supports the findings of the study. Finally, credibility of the findings was

increased by researcher reflexivity. In this process I considered the subjectivity of my etic perspective and engaged in the process of removing or revealing unintended bias that may come from my assumptions, worldview and background (Borg et al., 2010). That is I reviewed how I formed a particular perspective and I examined this and shifted my views when necessary (Fisher, 2009). Reflexivity allowed me to check if I was forcing my interpretation on the data and ignoring other useful interpretations. Reflexivity was documented in a researcher's field journal or in memos during analysis. Because of thick description, the audit trail and reflexivity the reader is able to evaluate the findings. This contributes to the confirmability of the study. In turn, this is a factor in determining the impact of the findings on practice and on the research community.

3.4 Ethics

Guidelines in the Tri-Council Policy Statement indicated that this study did not need to be reviewed by the Behavioral Research Ethics Board of the University of Saskatchewan. This study involved public textual data, therefore it had no participants. Articles 2.2 and 2.3 of the Tri-Council Policy Statement indicate that this study was exempt from REB review, yet it was conducted with ethics in mind and under the supervision of senior researchers.

To prepare an ethical study, methods for minimizing risks were considered. This study involved minimal risk, meaning the potential for harm was no greater than harm participants will encounter in their daily activities or have already exposed themselves to. In this case parents had publicly posted information on line; therefore they already were assuming the risk of sharing their information on line. Robinson (2001) provides a discussion regarding the ethical use of unsolicited narratives. She indicated that if a person has posted something online in a public way the poster is relinquishing control over her posting to share the information with a wide audience (Robinson, 2001). Robinson (2001, p. 711) conveyed that "users that have posted information to a freely accessible asynchronous forum expect that persons unknown to them may read, share and comment on their postings." What the parents had done by blogging is similar to posting something on a publically accessed bulletin board. In essence they had no reasonable expectation of privacy of the information they had shared and by their actions they had given consent for the public to view their writings and comment on them. For this study online postings were selected which were obviously public; where the author was aware that anyone can read them. Her

awareness was assumed because the web forums informed participants of the public nature of the postings. The Association of Internet Researchers (2002) asserts "the greater the acknowledged publicity of the venue, the less obligation there may be to protect individual privacy, confidentiality, right to informed consent" (p. 5). This research group takes the position that in the case of the current study informed consent was not required for the use of the public online documents as data. Article 2.2 of the Tri-Council Policy Statement indicates that if a study relies on publicly available information with no expectation of privacy and is protected by other legal means the study is exempt from review as there are no participants to protect.

Another viewpoint considers when using online documents one must decide to treat the writers as authors or as subjects (Himma & Tavani, 2008). As authors they would deserve to have their writing acknowledged and cited; yet in doing so a violation of the ethical standard of granting them anonymity would occur. Article 2.3 of the Tri-Council Policy Statement indicates that in observation of public acts a review is not necessary but when reporting research results individuals should not be able to be identified. In light of this, the current study treated the documents authors as observation subjects who deserve anonymity; thereby preventing any harm or embarrassment from using their publically posted documents. Researchers grant their participants anonymity as a way of minimizing harm (Himma & Tavani, 2008). The current study balanced the participant's right for anonymity versus the need to increase trustworthiness by thick description, which required the use of quotes. It could be argued that since the participants publicly posted the documents on the internet it seems that they had given consent for this information to be seen by the public; therefore quotes can be used in ways that are respectful of how they originally wrote their blog. More specifically, quotes were not taken out of context in a way that changed the meaning of a statement or that would do harm to the authors. Findings were written in a way that will also protect the well-being of the bloggers' children. This was done by being careful to write in a way that was respectful to the child and allowed them to be anonymous as possible considering the publicly posted information. Identifying information (names, pseudonyms, city names and third parties) was removed to ensure anonymity. Additionally, by using multiple documents general themes were reported in a way that contributes to anonymity of the participants.

In essence, the current study used public documents posted by parents on a virtual public bulletin board, therefore informed consent was not required because the documents were public; yet to do no harm the current study was written in a way to ensure anonymity and that avoided distorting their statements. In this way the current study met the guidelines of the Tri-Council Policy Statement and did not require a review by the Research Ethics Board.

CHAPTER 4: FINDINGS

This chapter presents findings based on the analysis of the six documents that made up the data base of this study, which resulted in a collection of themes about the parental experience of participating in Brain Balance. First I describe the database and present a table summarizing the parent-child profiles. Then findings are presented thematically using the research questions as an organizing framework.

4.1 Overview of Data Base

The findings of this study were derived from the online writing about Brain Balance by six different parents of six children with a variety of neurobehavioral disorders. Documents in the study were either blogs or shorter postings on forums. The sample was chosen to capture diverse parental viewpoints, parents holding both critical and supportive opinions about Brain Balance. For the purpose of granting the authors of these online documents and their children anonymity their names and identifying details in the postings were removed and for the purpose of discussion replaced by a pseudonym (although it was understood that a few parents (not all) already used methods of concealing their identity). Quotes are reproduced exactly as posted.

The online documents of this study included three blogs in entirety, a specific posting from a large blog of many years and two postings from web forums. The three large blogs had postings that were entered over the entire period the child was in the program while the other shorter postings were more summary in nature. The three larger blogs were high in detail, while the shorter postings had specific relevant comments. The number of posts the parents wrote varied: Paula wrote 47 posts in her blog, Linda wrote 37 lengthy posts in her blog, Mary wrote 24 posts in her blog, George wrote one lengthy post and responded to comments on his blog, Brenda wrote one post in a forum and Anne wrote three posts in a forum.

Table 1.1 Identifying Details of the Analysed Documents

Pseudonym of Parent	Pseudonym and Age of Child	Disclosed Diagnosis of Child	Participation in Brain Balance Program	General Overall Viewpoint of Experience
Paula	Peter aged 8	PDD-NOS, ADD, anxiety, depression	12 weeks	Reports improvements attributed to program
Linda	Luke aged 11	ADD, Tics, Anxiety, slow processing	12 weeks	Reports improvements attributed to program
Mary	Maggie aged 8	Autism	Pre Brain Balance 11 months Brain Balance – 12 weeks	Reports improvements attributed to program
George	Junior aged approximately 13 years	Autism	None but reacts to Brain Balance advertising	Critical of program
Brenda	Brad age not disclosed	Autism	In program 3 times for 12 weeks	Disappointing results from the program
Anne	Allan age 9 years	AD/HD	12 weeks (may have attended prior to 2009)	Critical of program and results

note: Paula, Linda, and Mary wrote lengthy blogs and George, Brenda and Anne wrote short postings of a page or less.

4.2 What is it Like for Children and Parents Participating in Brain Balance?

Six main themes emerged that were common to the three parental blogs whose children did the program. The six themes are: (1) Components and Stages of the Program, (2) Encountering Brain Balance Theory as a Rationale, (3) Challenges Experienced as Result of the Program, (4) Coping Methods, (5) Noticing Changes in Child's Functioning, and (6) Debating the Cause of Change in Child.

4.2.1 Components and stages in the program. Much information was posted about the different aspects and stages of Brain Balance that families generally go through. The different

components consist of parts of the program that were done at home and those done at the center. The home program included primitive reflex exercises, sensory/motor exercises, listening to brain balance music, implementing diet changes, administering supplements and adhering to recommended lifestyle changes (e.g. limiting screen time, improving diet). Paula provided a description of some of the home exercises she had to get Peter to do three to five times a day.

> Usually he likes to do the four eye exercises first. Then he moves on to the primitive reflex exercises. What are they? Primitive reflexes are automatic and repetitive movements that are essential in the womb and during early development. They shouldn't be active after a child's first year and if they are, they can hinder the appropriate brain development. Peter has to do eight exercises to help him eliminate the presence of the rooting, spinal galant and moro reflexes (to name a few). When he's done with those, he strengthens his core. It's an active ten minutes; he's a real sport and does them without much fuss.

Luke's mom Linda gave a very detailed description of her introduction to the home aspect of the program:

> They gave me my parents' home guide, which is a 3-ring-binder with all kinds of documents. I signed permissions for them to communicate with Luke's teacher, and the director will even be going to visit with Luke's teacher to help prepare her as well. She gave me some regression examples of other 10 year olds: one started crawling again! One started having an imaginary friend. One mild mannered boy had a tantrum toward his teacher at school!!! oh boy!! More documents in the binder had FAQs and all kinds of program info.
>
> There's a nutrition section that tells us to eat healthier - no sugar, soda, fast food, chemical, processed foods, MSG, artificial sweeteners, sports drinks, etc. Luke is very resistant to a lot of this, and I find myself having some too. Admittedly, we hit the Wendy's drive through about once a week to grab the kids a chicken snack. And I told her that, realistically, he will be having slices of birthday cake or root-beer floats, etc. on occasion - don't we all??!!! But, you get the general idea.
>
> As far as screen time, no more than 30 minutes a day (not including school related computer use) - but including tv, video games, ipad, gameboy, computer games, etc.
>
> We have a bunch of exercises he has to do 3 times a day at home. There are groups of exercises, and for this week she is just having us learn and do the primitive reflex exercises. She says they should take about 10 minutes to complete, but we tried them tonight and they took 20-30 minutes, but we're still learning them. They're simple, but i can tell we're going to tire of them quickly!
>
> We were given a cd of music designed to stimulate the right hemisphere (his weaker side) - he has to listen to it 3-4 times a day for 15-20 minutes with his left ear only. So, using an ear bud in the right ear on and ipad, or if we play it through the stereo he has to put an earplug in his right ear. So tonight, we put it on the stereo and we all put an ear plug in our right ear. The cd reminded us of one of those nature cds combined with a Halloween

> scary sounds cd, and after 20 minutes we were all sick of it. I felt nauseous and Luke had a headache and brother couldn't focus on his homework haha!
>
> There will also be eye exercises, deep breathing exercises, and sit ups and push ups, and others, as we get more into it. But for now, just the primitive reflexes, so I'm getting him up 20 minutes early before school tomorrow, we'll see how we do. He felt some rug burn tonight from some of the floor exercises, so we laid out a blanket.
>
> We have to keep a daily food journal for all 3 months of the program, along with any behavior observations; and a log of all the exercises completed each day along with observations about uncharacteristic behavior. We will meet with a nutritionist 5 times, and for check ups with the director a few times. We can email, phone or chat any time we have questions. We also got a kit to take to a lab for urine and blood tests. Once those results come back we will meet with the nutritionist for a consult.

Mary also detailed some of the home exercises they did with Maggie.

> ...detailed primitive reflex exercises to do 3-5 times a day. These exercises are simple but very powerful. Unfortunately, even as simple as they are, we will have to work very hard to get Maggie to do them. We are also going to start working on sensory-motor exercises that target the right brain as well as listening to specific music that has been arranged just for right-brain input.

Paula wrote of her program orientation with the center's director, who

> ...stressed the importance of parental involvement. She explained that this is not a program that ends when we walk out the door. She took me through the homework – about 15 exercises that need to be done 3-5 times each day.

Mary wrote of the supplements she had to give her daughter during the program.

> Maggie is taking 14 capsules, 2 doses of fish oil, and 2 doses of B-complex daily. We are working up to 28 capsules, fish oil, b-complex, and one dose of 3 other powdered supplements daily.

Obviously, the home aspect of the program was demanding and involved a family adapting to all the demands on time and organization it took to implement changes the program required. This aspect of parent involvement was emphasised to all the parents in the study. The implication could be that the parents' carry a heavy responsibility for the success of the therapy.

In addition to the program at home, there were components of the program done at the center: sensory-motor exercises (including Interactive Metronome), cognitive/academic exercises and consultations with the director and the nutritionist. Here Paula gave an account of her experience with the activities at the center.

> At Brain Balance, he heads back with Ellen and his binder and comes back to me an hour later on his own. I have no interaction with either of the women he works with. I'm not even sure of the name of the woman who does the cognitive portion of the session. And as anyone who has kids knows, I cannot get any info from Peter. He tells me nothing, No names. No drills. No details. No funny moments. N-O-T-H-I-N-G-! They say they don't share because they need to protect their product and don't want other therapists stealing their secrets. Also, since the sessions are so short and intense, they don't have the time to talk to parents on a daily basis. Makes sense but I'm still hungry for information and don't want to wait till our first parent meeting. It doesn't happen till we're 1/3 of the way through the 12 weeks. Last week I asked Ellen if I could take a peak in on his session to see what he does. As gracious as ever, she took me back to Betty's office to spy through the two-way mirror. There he was in this crazy sensory motor gymnasium walking on the balance beam. As if that was not hard enough for Peter to master, he had some kind of band on his ankle, another one on his wrist, an earplug in one ear and wacky glasses that were mostly black. How could he not tell me any of this? Does he realize how funny he looks and how silly what he's doing is? I guess not. Next, he went on to do side planks and climb on the monkey bars - with all apparatus in tact. He was very pleasantly moving from task to task and seemed to be having fun. I asked if all the kids were so compliant and Ellen told me that he's really easy. She kind of has to say that though, doesn't she?

The parents also wrote about the program's different stages. The stages consisted of the initial evaluation; this included sensory-motor evaluation and academic testing using the WIAT (Wechsler Individual Achievement Test); orientation of parent to program (described above); appointments at the center 3 times a week for 12 weeks, lab testing (blood and urine samples); initial nutritional consultation and four follow-up consultations; three progress reviews (every four weeks) and re-evaluation (post testing). These stages were exemplified by the following quotes from the parents.

Paula told of some of the tests used in evaluations at the center

> Today Peter and I went to Brain Balance for the second of two re-evaluations. He worked in the sensory gym with Sue while I sat in reception re-completing the same written evaluations I filled out when we started - The Brown Scale (measures ADD/ADHD), the GARS (an autism rating scale), The Hemispheric Checklist (measures Motor, Cognitive, Sensory, etc), The Sensory Profile and the BER (Behavioral Evaluation Record).

Paula described the lab testing that was required to implement the program.

> ...have a Metametrix test done on his blood and urine. They test for 90 food sensitivities. Any foods that come up have to be removed from his diet immediately... The good news is that towards the end of the program, when his gut is mended, we will gradually reintroduce the foods.

Mary gave her perspective on the lab testing required.

> Furthermore, we have to get a blood test....a daunting task. The last and only time we had blood drawn from Maggie was when she was 3. It took six people to draw the blood because they had to hold both legs and arms and head still. I was horrified and it brings tears to my eyes and sickness to my stomach thinking about it. The blood test will tell us what if any food sensitivities she has. When we know that, we can begin to change her diet per the nutritionist guidance.

Linda gave a detailed description of the purpose of the lab testing done as follows:

> In their words (copied from the 12-page guide you get to help understand your results): "The Triad Profile combines three separate laboratory tests providing easy customization of diet and supplementation: The Organix Profile evaluates products of metabolism and identifies specific nutrients you may need that are critical for energy production, nervous system function, elimination of toxins, protection from cellular damage, and metabolism of nutrients. The Amino Acid Profile identifies levels of certain amino acids, the components of protein that are essential for healthy functions of nearly every metabolic process in your body. The IgG Food Antibody Profile identifies foods you are reacting to that may be putting undue stress on your body; it can also reveal digestive problems that may need improvement." In addition to the 12 page guide to the results, I got 12-pages of Luke's results.

Linda, also, gave a detailed account of the results of their nutritional consultation after the lab result.

> At our first nutrition meeting, they recommended having him on a multi-vitamin, fish oil with at least 500 units of DHA, and a probiotic. We were already using a multi-vitamin, fish oil, probiotics and Juice Plus. However, once we got the blood and urine test results that showed us his food sensitivities, we realized the supplements we were using weren't right for him. The multi-vitamin had soy in it (which he is allergic to), the fish oil didn't have enough DHA, so I switched to a purely DHA version made from calamari. Once he's done with Brain Balance, he can return to the complete Fish oil we were using since it has Omega 3-6-9s instead of just the DHA. The probiotic we were using had milk and soy in it (he's allergic to both) and wasn't strong enough. They switched him to one that has 10 billion units from 5 different strains. And he's continuing to use Juice Plus, but I've bumped him up to the adult does, which he was ready for anyway.
>
> After the nutrition meeting where we got his blood and urine results, we got a recommended list of amino acids and multi vitamins. We had the option of purchasing them ourselves at the store or ordering customized ones that would be free of allergens and formulated to his specific needs. We chose to get the customized ones, uncapsuled (that gives us the option of using them as a powder mixed into food, or putting them into capsules ourselves). Uncapsuled also saved us over $100!!! We also ordered two extra amino acids in capsules. (Glycine 3 capsules a day (an amino acid that his tests determined he needed), L-Glutamine 4 capsules a day on empty stomach (another amino acid he needs).

Progress reviews were an important aspect of the program and the parents described them in various detail. Here is Linda's description of Luke's third progress review. These progress

reports happened every four weeks and the details were used to assess change. Here the details gave by Linda allow the viewing of the components of Luke's program.

> Luke's report showed the following: (Areas that he has met the level goal are in bold) - I'm going to include data from all 3 progress reports.(PR- Progress Report)
> **Visual Activities**:
> Optokinetics (Tracking) - Luke started the program at a level 7, moved to a level 10 at the first progress report (4 weeks), moved to a level 12 at the second progress report, is now at a level 14 - the end goal is level 15.
> VOR (Blur in Motion) - Start: Level 12, PR1: Level 15, PR2: Level 15, PR3: Level 15 Goal Level 15
> Visual Stimulation (various eye glasses with lights and other stimulation): Start: Level 1 (everyone starts here), PR1: 4, PR2: 7, PR3: 7, Goal: 7
> **Hearing:**
> Stimulation: Start: Level 1 (everyone starts here), PR1: Level 2, PR2: Level 3, PR3: Level 3, Goal: 3
> Processing (wearing a headset with different words coming into each ear, having to comprehend from the left ear): Start: AGE 7, PR1: Age 10, PR2: Age 13, PR3: Age 15, Goal: Age 11 - Luke said that he memorized the words and sentences which helped him progress - this bothered me because it's not necessarily processing improvement as much as memorization (which he did need to work on anyway...)
> **Touch:**
> Tactile Stimulation (different buzzers that are attached to the kids ankles and wrists, upper arms, etc.): Start: Level 1 (everyone starts here), PR1: 4, PR2: 8, PR3: 8, Goal: 8
> **Fine Motor** (linked to Brachiation which will be shown below in "Core Muscles"): Start:AGE 5 (whoa!), PR1: AGE 8, PR2: AGE 11, PR3: Age 14, Goal AGE 11
> PRNG (How they handle being spun, dizziness): Start: Level 3, PR1: 6, PR2: 7, PR3: 8, Goal: 8
> **Proprioception** (awareness of their body's location in space): Start: Age 9, PR1: Age 11,PR2: Age 12, PR3: 15, Goal: 11
> **Core Muscles:**
> Supine Core (stomach): Start: Age 6, PR1: Age 9, PR2: Age 11, PR3: Age 13, Goal Age 11
> Prone Core (Back): Start: Age 6, PR1: Age 9, PR2: Age 10, PR3: Age 13, Goal: Age 11
> Lateral Core (Side): Start: Age 6, PR1: Age 8, PR2: Age 9, PR3: Age 12, Goal: Age 11
> Brachiation (pull-up with hands facing away from body - directly related to Fine Motor - above): Start: Age 3 (yowza!), PR1: Age 6 (in just 4 weeks time!), PR2: Age 8 (at this time we were worried he wouldn't reach age 11 in the next 4 weeks), PR3: 12, Goal: Age 11
> His starting numbers in this above section explain a big part of why Luke has struggled so much in athletics over the years, and why he was doing so much better recently.
> **Synchronization Activities:**
> Balance Beam (doing various activities while on a balance beam): Start: Age 8, PR1: Age 10, PR2: Age 11, PR3: 13, Goal: Age 11
> Gait and Aerobics: Start: Age 8, PR1: 11, PR2: Age 11 (my new report had this at a 12???), PR3: Age 13, Goal Age 11

> **Interactive Metronome** (measures the ability to keep a beat): Start: Age 12 (they were surprised by this, and figured it was due to the fact that he plays an instrument), PR1: 12 (they were ok with no progress since he started above age level), PR2: Age 13, PR3: Age 16 (they were pretty amazed by this considering he had been above age level to begin with - he improved by 4 years in 3 months this area), Goal: Age 11
> **The Things he's working on in the Cognitive Room (Educational Room)** - all activities that are weak in the right side of the brain:
> Making Inferences
> Drawing Conclusions
> Math
> (He's no longer needing to work on Main Idea)

Generally, three parents who wrote a detailed blog went through the same process to participate in the program, the one exception was Mary and her daughter Maggie. They had the added component of the Pre-Brain Balance program because of the severity of Maggie's symptoms of Autism. Children who were not quite ready for the program at the center were assessed and assigned exercises to do at home first as a way to prepare them for the regular program. Additionally, these children may do more than one block of therapy at the center depending on their progress. Mary's blog described some of the activities in the 11 months of Pre-Brain Balance. These activities included

> After reviewing Maggie's case more, BB has decided that it would be a waste of our money to have Maggie come now. The good news is that they have given us detailed primitive reflex exercises to do 3-5 times a day. These exercises are simple but very powerful. ...We are also going to start working on sensory-motor exercises that target the right brain as well as listening to specific music that has been arranged just for right-brain input. Furthermore, we have to get a blood test.... The blood test will tell us what if any food sensitivities she has. When we know that, we can begin to change her diet per the nutritionist guidance.

Clearly, the components and stages of the Brain Balance program add up to a demanding and intensive experience for the parents and children involved. The description gained from these blogs gave insight into the complexity of the program and the difficulty of determining what components were helpful. From the description the multiple areas that were targeted by the intervention are apparent, such as biochemical/digestive, gross motor abilities, temporal processing, cognitive/academic abilities and some sensory areas (visual, tactile, auditory). To justify the use of these therapies the parents in the program all spoke of the next theme of participating in the program; that theme being encountering Brain Balance theory as a rationale.

4.2.2 Brain balance theory as rationale. The theory behind Brain Balance was used to motivate parents to participate in the program and was considered in their decisions to do the program. Also, parents used this theory as a way of communicating with readers why they were doing certain activities with their child. Mary told her readers of an activity they were doing in Pre-Brain Balance by explaining theory behind the activity.

> One activity in the BB program is training the smell sense to start working. Since Maggie has a right-brain deficiency we will be putting essential oils like peppermint, eucalyptis, and other strong smelling scents on her right collar. This has been proven to help picky eaters. Think about it...if we didn't smell the chocolate chip cookies and we had never eaten them, would we want them? We eat with our nose and eyes first and then our taste buds. If you have a brain imbalance none of those senses work correctly.

Paula shared her version of being given a theory rationale by the director of the center when she was resistant to a lifestyle change.

> Director explains that playing video games and watching tv both activate the left side of the brain. Since Peter's right hemisphere weaker, this makes the disparity between his two hemispheres even larger. Exactly what we want to avoid. She reminds me that the premise of BB is not to hover safely where he's capable and comfortable; the goal is to strengthen what's weak and make him uniformly strong across all areas.

Linda shared this about her understanding of the theory behind the program,

> When you are in the program, they are doing exercises 3 times a day, and sensory stimulation at the center 3 times a week, so the brain is receiving a ton of input and growth and it's almost overwhelming the brain, but in a good way. It is getting the one weak side caught up to the strong side, at a very rapid rate, and once the program is done, the brain can take off with both sides working together over the next year.

At other times parents cited the theory as an explanation to their child of why the child had to do certain aspects of the program. In these cases it had the effect of getting the child to comply with the treatment. Linda discussed the theory behind the diet changes Luke had to go through as a way of getting him on board with the program.

> We learned that Luke has a condition called Leaky Gut. I don't have a full understanding of it, but basically, his insides of his intestines are so swollen and irritated that they are not filtering the foods that get absorbed into his blood stream. So large amounts of food are entering and causing a reaction in his blood and other parts of his body, specifically his neurological system. When we eat nutrients there are is a chain of conversions and reactions that take place to utilized the nutrients properly, and when you are missing key components of the system, you end up with stored and unused amino acids and other

> things that cause dysfunction on many levels. I am so relieved to see these results on paper, that specifically support his symptoms - it feels like validation. I am even more excited that once he gets on these supplements, things will start to change for him! And eventually, his body should produce the needed items without so much supplementation. For now the extra strength probiotic and the high DHA will help heal his gut and his brain. The health of the gut and the brain are very connected. I explained these things to Luke after my meeting, and he is very excited too.

The theory behind Brain Balance played a part in some parents' decision to do the program. Here Paula cites considering the theory behind Brain Balance as part of her decision making process to do the program.

> I read his book, Disconnected Kids, and what he writes makes a lot of sense. He believes that many of the disorders that are popping up with alarming regularity in every first and second grade classroom are manifestations of one underlying condition called Functional Disconnection. In his book, he suggests that the behavioral, academic, and social difficulties these kids suffer from are caused by an imbalance between the hemispheres of their brains. He predicts that if you close the gap between the two sides of the brain, issues like distractability, low muscle tone and other Peter behaviors will happen less - and maybe even go away. His theories serve as the foundation for the work done at Brain Balance.

One parent in particular, George, took exception to the use of the theory as a rationale to do the program. He concluded that the claims in a Brain Balance advertisement were outrageous and decided not to consider this treatment for his son with autism. George stated,

> I want to see reviews by credible authorities before I gamble my son's development, and possibly his well being, on "revolutionary" treatments.

Other parents also had their moments of thinking critically about the theory behind the program. Here for example Paula was wrestling with the legitimacy of the theory behind Brain Balance,

> Sound too good to be true? That's what I'm scared of.

And three weeks into the program Paula wrote :

> She explained that there are two goals for each sensory motor session – 1. they want the kids to make functional gains by moving up levels (this is what he earns the stars for) and 2. they want to provide targeted stimulation to his weaker hemisphere so that it can grow and catch up. A well-known neurologist at UCSF, Michael Metternich, wrote:
>
> > Research has shown that engaging the brain's plasticity to drive beneficial changes requires exact stimuli delivered in the appropriate sequence with precise timing. The training must be intensive, repetitive, and progressively challenging. Individuals must be strongly engaged in the training, paying close attention. It's all about the mind's vitality–nurturing it, reclaiming it and giving it strength.

> According to Betty, this is the driving principle behind the program and this approach is what makes it different from other programs. ... It all makes sense and I want to believe but the cynic in me (the one who keeps telling me not to get too hopeful) is still skeptical. Doesn't it sound a little hocus-pocusy? I think it does and I wouldn't be shocked one bit if Cathy and Ellen invite me in for a séance being led by Betty. But if Peter keeps smiling as much as he did this week, I'm ok with a little magic and am 100% ready to start drinking the kool-aid. Assuming it's dairy-free.

All who encounter Brain Balance will contend with making sense of the theories that are given as rationales for aspects of the program. The majority of parents are on a steep learning curve to interpret these statements and are left with evaluating these claims as best they can. One of the parents immediately rejected the claims of Brain Balance and looked no further whereas the other parents in this study forged ahead to see what the results of the program would be. They all did their own 'experiment' and shared the results with their readers.

4.2.3 Challenges experienced as a result of the program. The program required changes that could be effortful and difficult. All the parents who did the program experienced challenges that had to do with implementing the home aspect of the program, motivating their child to participate and experiencing conflicts with current lifestyle to do the program. The following are examples of some of the challenges Paula, Linda and Mary experienced while participating.

Paula:

> Another one of BB rules limits screen time to one hour each day. When Betty shared this one I resisted. Peter is addicted to video games and I am used to defending his playtime.
>
> There's good news and bad news. Good thing is that there's only one thing we need to remove. Bad news is that it's dairy.

Linda:

> He's also getting less sleep because he's having to get up earlier in the morning, and stay up a bit later at night, to fit the exercises in. He's also falling behind on homework because he doesn't always have time to get to it between the sessions/exercise/typical family activities. This time of year always seems to fill up with school activities and homework demands as everything gets crammed into the end of the school year.
>
> It's just a lot for me to stay on top of, with 3 kids home and all their needs. It's also a busy season for my husband's job, so the full load of the program is pretty much on Luke and I.

> We listened to the music again - one song had what we called "Chanting monks, rain, and howling coyotes." This time only Luke did the earplug and he and brother both got headaches from it. It's not the least bit pleasant to listen to.
>
> We are really struggling to get in 3 sets of exercises per day. Some days we only get them in once. Luke has had to start doing them largely on his own because we're trying to squeeze them in between activities while I prepare for the next place we need to be. We also just realized the other day that we've been completely leaving out one exercise for a couple weeks, without even realizing it. We've been trying to make a rally to finish out our last month strong, but we're still struggling. He also has to take all the supplements at different times all day and that's been hard to stay on top of as well.

Mary:

> Since then we have been going through all sorts of emotions as we started to contemplate the costs and the details of maintaining two households and selling our house and getting rid of things we don't need, and even what to do with the cat because cats are difficult to move(I know some of you are wondering why even think about the cat but we love him).
>
> Maggie has never taken a supplement in her life. She won't even keep cold medicine in her mouth. No high fructose corn syrup, no french fries, no msg, yada yada.

Regardless of a family's circumstances when they commit to doing this program they will be challenged in some way by it. The challenges will depend on the family's resources and situation. As evident from these parents' comments, challenges might include economic challenges, logistic challenges, unwanted effects on other activities, children disliking the program and children's symptoms making it difficult for them to cooperate. It is a given that when doing this program that it will require coping skills to adapt and persevere.

4.2.4 Coping methods. Parents used multiple ways of assisting their child and themselves in adjusting to the demands of the program. These coping methods were diverse. They included anything from informal social support from staff and other parents in the program to spiritual methods. The following spotlights some of Paula, Linda and Mary's coping methods.

Paula:

> It's not too often I find a mom of a kid with issues that's willing to open up. But in this environment where all of our kids have something going on, it feels safe and most of the moms are willing to share stories and support. Coming here has become a nice outlet for me too.

I am peppy and try to minimize what's going to happen. It'll be OK. It barely hurts. By the time you count to three, it'll be done. On and on I try to reassure him. Lies all lies. Getting blood taken is truly one of the worst things that could happen to his sweet, little arm.

To make Peter feel like he has some control, we let him chose the order. (of his exercises)

I remind Peter that it's only for 3 months (which seems like a lifetime to a seven year old) and that we will go to our favorite place – Sweet Orange – for our final send off to Fro Yo (Frozen Yogurt). But that this is the last one for a while. He starts calming down. I tell him I am going to figure out ways to make him great cookies. And we'll find fake ice cream that he likes. I promise him that we will find some yummy foods for him to eat. The tears are gone. He says Alright Mom, I know you'll make it ok. And almost in tears myself, I promise that I will.

Linda:

We're doing extra reps on the exercises when we do get them in, to hopefully make up for the missed ones. Although I know it's the frequency that matters as well. I am trying to remind myself that, right now, for Luke, Brain Balance is the priority of how we spend our time.

Mary:

My reading of Morning and Evening today comes to mind: "Come unto me all you that labor and are heavy laden and I will give you rest." This is a promise that I must cling to in the next few weeks.

My friend, Mindy, posted a quote today that struck a chord with me. "Never give up on a dream just because of the length of time it will take to accomplish it. The time will pass anyway." - H. Jackson Brown I have learned the old-fashioned way throughout life and especially this trial with Maggie that if I give my all today, then the todays will add up. We will not be "on" everyday because of our humanness. We will fear and doubt and procrastinate and have bad days, but we must keep striving because our diligence will pay off in one way or another.

I'm thinking there is just no way, but God is bigger than all of that so we'll see what kind of parting-of-the-Red-Sea kind of moment he will give us there. Ha! We are speaking with the director of BB to brainstorm on ways we can help her work toward getting the supplements in her system among other issues with the program.

Social support, problem solving, positive self-statements, setting goals, time management, inspiring reading and relying on faith in a higher power were a few of the coping skills of the parents in this study. These parents were a tribute to the resiliency of the human spirit as they

found ways to cope with the challenges they faced in supporting their child. Again this coping theme connects to the last theme, for which they were coping, and that is looking for changes in child's functioning.

4.2.5 Looking for or noticing changes in child's functioning. Parents looked for or saw changes in their child's functioning. This may include having others confirm or notice changes or lack thereof, as well. Paula, Linda and Mary all made statements illustrating to this theme.

Paula:

> To you, this may sound like a normal night out with an 8 year old. But it's not typical for us. In the past, he wouldn't have been focused. He would have walked all over the restaurant- tripping as he wandered. He couldn't have stopped asking when he'd be allowed to play video games next. And he would have been so distracted by all of this that he wouldn't have been present with us.

Linda:

> I think we are starting to see some real results. They are happening almost daily and I keep jotting little things down on scrap papers so I won't forget to put them on here, I know I'll forget some though.
>
> Not only am I noticing changes, I'm also getting comments from the Grandparents and John.

Mary:

> We have not seen any changes yet, but then we didn't expect it so soon either.
>
> ...director of BB is going to test Maggie's primitive reflexes and perhaps some of our hard work will pay off because some of the reflexes may be gone which is what we want. We know we are getting close with the Galant reflex

For all families that participated in Brain Balance a reoccurring theme was anticipating and looking for change. If they were investing all their efforts, time and money they were naturally expecting a result and would naturally be more watchful for this than in a typical time of development.

4.2.6 Debating the cause of change in child. Debating the cause of change in their child involved parents' online writings that focused on trying to make a judgement of what caused a change in their child. As parents went through the program they wondered about factors contributing to change, such as maturation.

Paula:

> Is this improvement because he's two years older? or because of all the work he's doing? or a combination of both? I don't think there's a way to know

Linda:

> He's also slimming down a bit. I'm not sure if it's the exercises, or his posture improving, or if its from his new diet (from either not having enough to eat, or from his body not being all bloated from eating things it can't tolerate and process).
>
> I think that probably all of us would benefit from the blood and urine tests, and by using the elimination diet if needed, and the customized vitamins and amino acids. I imagine that some day, annual check-ups will include these tests and recommendations, and child well-checks will include checking for lingering primitive reflexes with a hand-out on how to get rid of them if they're still there. This is all either cutting-edge, or coo-coo! We're hoping for cutting edge

It is evident that both Paula and Linda were having a hard time making a judgement about what was causing the change in this multi-modal program.

4.3 What are Parents' Judgements about Doing Brain Balance?

Five themes related to how parents evaluated the program were found in the three detailed blogs from Linda, Paula and Mary: (1) Initial Judgements about the Program, (2) Reactions to Quality of Service at Center (3) Comparison of Brain Balance to Other Therapies, (4) Overall View of Program, and (5) Final View of the Program's Impact on Child. Some of these themes were also in the shorter postings of George, Anne and Brenda.

4.3.1 Initial judgements about the program. Initial global judgements parents made during the decision making process about the program included that it was too expensive, exercises could be done at home, the home program seemed too demanding, it was not a good fit for child, was simplistic, and they risked wasting time and having their hope dashed.

Paula:

> He likes what he read but thinks the fee is too high and that we can do all the exercises ourselves at home. Sadly I admit that while I am committed to helping Peter, I know my limitations and I just don't have enough spare time in my day to take this on.
>
> I worry that it's all hype and in four months, we will be in the same place we are today – just with less money and slightly broken hearts.

Mary:

> She is severe and we do not expect her to be able to complete the assessment.
>
> We are cautiously optimistic about BB for Maggie.
>
> We also were dealing with disbelief in BB. How could the solution be so simplistic? Were we so desperate to find a solution to the autism problem that we were believing yet again that what we were trying this time was the answer?

George's initial judgement of Brain Balance was critical, as evident from his writing.

George:

> I wait for credible authorities like the Surgeon General and the American Academy of Pediatrics to review the research literature and offer guidance on what constitutes evidence based effective autism treatment. The unbridled enthusiasm of the co-owner of a proprietary treatment doesn't do it for this autism parent.

These initial judgements represent parents coming to terms with committing to doing the program or not. Based on these initial judgements only a select group of parents could commit to this program – that being those who believed in the credibility of the program, those with enough financial resources or willingness to go into debt, and those with willingness for the lifestyle changes.

4.3.2 Reactions to the quality of service at center. All the parents who did the program posted reactions to the quality of service at a Brain Balance Center. Parents had various reactions to how things were done such as an awareness of differences between centers, liking some aspects of service and feeling other things were not done well. Parents even made judgements about the quality of information given. Paula, Linda, Mary and Anne's comments gave rise to this theme.

Paula:

> BB changed the elimination policy (I.e. the length of time a food is removed from the diet)– it was eliminated for 90 days. They revised it to 30 days... When I heard about this change I was really annoyed. It conflicted with what I was told when Peter started and the glass half full in me couldn't help but wonder if it was a marketing decision more than one based on research – it's got to be easier to sign parents up when they only think they'll be eliminating for 30 days.

Linda:

DVD with videos of the exercises. They said they've been asking for one to be made for a couple of years and they just got it. I was also told that there are some changes in the way we need to do some of the exercises. Both of these tid-bits irked me a bit. I'm trying to be brutally honest on this blog.....I thought, I'm paying $6000 for this service and no one at this center knew the correct way to do some of these exercises???!!! We've been doing them wrong for a month, and other families did them wrong the whole time they were here! I try to bear in mind that this is a relatively new idea, much like going to a new school that's just starting out, or a new company, there are wrinkles that need smoothed out. But I feel like maybe you shouldn't be charging as much as another center that's been around longer and has all their ducks in a row. Anyway, we will make the corrections on the exercises.

She also recommended some products that I know aren't the best of what's out there, and some information that is outdated. This FRUSTRATES me. Luckily, I'm educated enough to make adjustments for Luke, but what about families that aren't??

(Following the mislabelling of a supplement) I shared my frustration over that with the center and they were apologetic and said it is only the 2nd time that has ever happened for them, the last time was 2 1/2 years ago. I also shared with them the frustration over Luke being held at a level in the sensory gym for several weeks because they hadn't explained the proper technique to him, and that once they did, he passed it, only to have them forget to give him his star! It doesn't seem like a big deal, but it motivates Luke. I was upset that #1, they didn't explain it to him, it held back his progress, which, in a program that costs $500/week is a big deal, and #2, when he finally passed it they forgot to give him his star! They also apologized for this, although one of them was defensive.

The owner told me that they held a meeting to make sure the things run more smoothly b/c they always want to be improving the program. I emailed my concerns, and they responded with emails, phone calls, and talking to me at the center. I felt like they responded well.

The dose she had originally told me to give him was only half of what he was supposed to be getting!!! That was frustrating because it made me feel like it could have healed faster if we'd been doing it right all along. I also didn't know that that supplement had that specific purpose, and we had often missed doses of it, so he really wasn't getting what he needed!

Mary:

I was so impressed with and encouraged by the care that they took in answering our questions and working at Maggie's pace. Even though they have only taken high-functioning kids in the past, they are taking Maggie as a

special case,

> ...tossing around the idea of taking Maggie to Brain Balance Center 2 in Other City because they are set up to teach more severe children one on one...Center 1 is still a fairly new center and are focusing on more high-functioning children at present.

Anne:

> The program has a great concept if it were managed as they described in the open house sessions.
>
> Brain Balance is very disorganized and inconsistent in their administration of their wonderful ideas.
>
> Even after explaining how outrageous their request was, no one ever contacted us from BB to discuss nor empathize with out disappointment.

From these comments it appears that there was significant variation between centers in how this program was administered. This mattered greatly to Mary as she felt her daughter could only be adequately helped at a particular center and she moved her family to get access to its service. Linda gave detailed feedback to the center her son attended and seemed satisfied that the center was trying to improve its service, yet Linda felt quality varied between centers. Anne's experience in particular makes it sound like the center her son attended did not live up to the marketing on which she was initially convinced by to do the program. This theme in particular represents a valuable area of inquiry, as clients feedback about quality of service is vital information for many stakeholders.

4.3.3 Comparison of Brain Balance to other therapies. Many of the documents illustrated that parents experienced Brain Balance in relation to other therapies. They were aware of the differences between the therapies their children had experienced.

Paula:

> It seems like Brain Balance is taking ideas from a lot of different doctors and theories and combining them into an intense 12 weeks.
>
> I know that it's not a forever commitment like all his other therapies seem to be. As much as I love chatting with sweet Ellen, I won't miss it when it's over. But with at least nine more weeks to go

Linda:

> I'm glad that we can go to one place for physical training, sensory therapy, tutoring, and nutritional counseling. If I were to try to do all of this on my own it would be a crazy busy schedule, or a long drawn out process over years.
>
> ...found Brain Balance, it brought so many of those findings together into one program; one that makes sense and is backed by tons and tons of research and success stories.

Paula and Linda both indicated that Brain Balance seemed to borrow from other therapies even though it claimed proprietary rights to its program. They thought that they could get similar therapies or resources elsewhere but they valued the convenience of one coordinated effort. Also, Paula's comment indicated that she saw other therapies as never ending whereas Brain Balance was perceived to be finite. George also provided a critical perspective on Brain Balance in relation to other treatments.

George:

> You must be aware of the professional literature which notes that non-evidence based interventions which have plagued autism treatment can waste family financial resources and the child's precious development time. In some cases they can directly cause harm to the child.

George's judgement about Brain Balance in comparison to other treatments was that it does not share the pedigree of being an evidence based intervention and therefore carries unforeseen risks. When confronted with Brain Balance parents cannot help but to compare it to other treatments, thus this theme was expected.

4.3.4 Final judgements about doing the program. Parents developed final judgements of doing Brain Balance. Both Linda and Mary concluded that the program was difficult to do. Linda went further and suggested that she felt it was overpriced and that a person could just pursue the component most useful to the individual- in her son's case the lab testing recommendations. Brenda indicated that there was a wide range of outcomes for individuals who do the program. Anne's overall view was that the program was mismanaged, therefore ineffectual and motivated by profit. The following quotes highlight these views.

Linda:

> On the one hand I can see how far he's come when I see these old behaviors popping up, but on the other hand I'm afraid that keeping them at bay is going to be too hard!

Within the first 2 weeks of Brain Balance, you are asked to use a lab and a blood draw facility to collect and submit blood and urine samples for testing. It is called the Metametrix Triad Profile. The results are so informative, I think anyone could benefit from this type of testing, I wish it were included at every child and adults wellness exam. The results tell you which, if any, foods you are having an IgG allergic reaction to. These are allergies that don't cause life threatening symptoms (anaphylaxis), but rather, milder reactions - emotional, mental, skin irritations, etc. The test results also identify which vitamins and minerals your are deficient in or have too much of, and explains what symptoms you would be experiencing in connection to those deficiencies. It also tests for yeast problems in your intestines. In their words (copied from the 12-page guide you get to help understand your results):

If you are considering the Brain Balance program, but maybe can't afford the time or money necessary, I would highly recommend testing for food allergies and an elimination diet together with appropriate supplements. Either the blood and urine testing Brain Balance offers, or maybe even better - find a Bax allergy elimination treatment center.

I'm just not yet convinced it's $6000 worth of value - I may feel that way at the end. Sometimes I feel like it's like buying sunscreen at the Water World amusement park when you've forgotten yours from home - you HAVE to buy it, but it's way overpriced. You don't regret buying it, but it leaves you feeling a little ripped off. I hope I don't still feel that way 2 months from now!

Mary:

Last year (in April I believe) we started doing Brain Balance Primitive Reflex exercises with Maggie. It was hard to say the least. Her brain, body, and heart just did not cooperate with our desire to rid her of reflexes that should have been gone long ago. Her body was stiff and it probably hurt a little too.

The BB program is very difficult....no surprise there. I can't go into the details of the BB program because it is just too much to type, but in summary, Maggie went to BB Monday, Wednesday, and Friday for one hour. In that hour, she was in the sensory-motor room where they did multiple activities that stimulate her brain, specifically strengthening her right hemisphere. We heard some screaming during the second half of the session and they said that is when they are doing tactile stimulation. Our part at home is difficult to say the least. We start out in the morning doing her primitive reflex exercises and then several times throughout the day we have to do a plethera of other activities to stimulate her right hemisphere and block the left

Brenda:

I know of some other bad parents whose children showed little improvement with the program. But to be fair, I also know some good parents whose kids did benefit using the

authors theories, inside and outside the Center. (Good and bad parents refers to how effective a parent was in implementing the program.)

Anne:

> If the program had been regulated and monitored in a professional manner, we might have seen some success without medication for ADHD.

Although the overall view of a parent depends on their experience, from this group of parents the overall views of the program seemed to be that Brain Balance is challenging and results are variable.

4.3.5 Final view of the program's impact on child. All five parents who participated in the program all conveyed the theme of having a final view of the program's impact on the child. The following quotes show the variability of this judgement by Paula, Linda, Mary, Brenda and Anne.

In the following quotes Paula related her reactions when she reintroduced dairy back into Peter's diet. She witnessed the return of his symptoms when the dairy was reintroduced and because of this she changed her opinion of skepticism in the need for diet changes to believing that they were necessary.

Paula:

> It made me cringe. I couldn't believe it. I love the old Peter but I didn't miss him and I really thought he was gone. Cathy was right. She said if it was going to happen it would be today. Holy cow. I guess she really knows what she is talking about.

> I am a skeptic. I don't want to believe that this behavior is connected to the reintroduction of dairy. I am terrified that these old behaviors, that I thought were gone are right there hiding under the surface. But there's no denying it. There has to be a connection...For now, I need to stop moping and relish the fact that the bridge I bought was actually for sale. Who would have thought?

Paula perceived Peter's change as coming from the dietary change of removing dairy from his diet. She concluded that Brain Balance helped her child and they know what they are doing. This is when she decided that doing Brain Balance can get results and was worth the expense.

Linda indicated that she felt like the changes that are most noticeable came from the supplements and diet change. She stated that the changes were subtle and not radical. She conveyed that she would continue to support her child with further dietary/allergy treatment and

continue lifestyle change in exercise. She concluded that Brain Balance helped her son but seemed lukewarm on recommending it wholesale and instead recommended the idea of the customized dietary testing.

Linda:

> I personally feel that the blood and urine tests results,
> combined with the elimination diet, have made the most striking, noticeable, differences for Luke during his 3 month session.
>
> My husband has made the comment a couple times that he's afraid the program might be making him worse (when he sees the regressions). And I certainly don't feel like we have "a completely new child" as other parents who've gone through the program have claimed. When I was checking references, I noticed that kids who fell on the spectrum at Aspergers and into Autism saw the most life-changing results, but kids with AD/HD saw milder results, and often saw the bulk of the results months after completing the program,
>
> I was really feeling like the most obvious changes
> in Luke came when we put him on the elimination diet, removing all the allergic foods from his diet. Together with his increased activity level through sports, made such a difference.
>
> If you are considering the Brain Balance program, but maybe can't afford the time or money necessary, I would highly recommend testing for food allergies and an elimination diet together with appropriate supplements. Either the blood and urine testing Brain Balance offers, or maybe even better - find a Bax allergy elimination treatment center.

Mary felt strongly that Brain Balance made many positive changes in her daughter. She endorsed the program for these changes and went so far as to put her younger daughter in the program as well. She saw Maggie as still having a way to go but no longer needing the extensive supports she once had. She attributed the changes in Maggie to Brain Balance.

Mary:

> Forfeiting the services that the CES Waiver (Funding for therapeutic
> services for autism) provided is a hugestep...a huge statement that we are making. We are essentially giving up
> $35000/yr worth of services until she is 18 or so. When Shawn told the service coordinator, he said that she was dumbfounded and that she didn't know of anyone just forfeiting these services. We know that there is a long line of kids
> waiting to get on the Waiver, kids with parents that have no hope, kids that need 24/7 care like Maggie used to be. We just couldn't in good conscience continue to take something that we didn't need. It feels so good to say that!"

...as well as adding a new member to the BB journey -- Sister!

...Well, the prison warden is now letting me outside for some much needed sunshine! Yes, that's exactly how I feel. I feel like I've been in a dark prison cell and I've been let out to get some sunshine. I just feel free and safe to go out with my children. Maggie has a long way to go but for now that sunshine sure feels nice on my face!

Brenda's child seemed to get worse from the program. He regressed in a way that required him to have more supports in the school. There was not enough information as to what this actually means (Was he more active? more demanding? It was not disclosed). Her judgement was that the program did not help her son in the way she hoped.

Brenda:

My child went through the Brain Balance Center program 3 times. Unfortunately during and after the program my son's regression has caused him to get less time in a general education classroom and more time in the spec ed classroom.

Anne indicated that Brain Balance did not help her son as expected and in her judgement this program should be avoided.

Anne:

Do NOT go to Brain Balance! We were one of the unfortunate families to have thought this program would have helped our 9yo child.

We did have to medicate our child but it did not cost us another $5/$8K.

From this small sample of parents it was apparent that there were a variety of judgements on the impact of Brain Balance on those who participate. Some parents attributed the positive change in their child to the program or an aspect of the program while others saw it as making things worse or having no effect.

4.4 What are the Impacts of Brain Balance on Parents and Children?

All six parents disclosed the effects the program had on them and their child. In the three detailed blogs seven common themes emerged. They were (1) Parent's Emotional Reactions, (2) Child's Emotional or Behavioral Reactions, (3) Changes in Lifestyle, (4) Impacts on Relationships, (5) Effects on use of Standard Therapies, (6) Child's Changes in Functioning and (7) Financial Costs. The shorter postings by Brenda, Anne and George also made comments that

reflected four of the seven themes (1) Parents' Emotional Reaction, (5) Effects on use of Standard Therapy, and (6) Child's Change in Functioning, and (7) Financial Costs.

4.4.1 Parent's emotional reaction. One of the most consistent impacts the program had on parents was an emotional impact. The parents felt a range of emotions throughout the program and at the end there was a lasting emotional reaction that was evident for many as well. Parents' emotions were in reaction to the difficulties in the program, reactions to the lifestyle changes, reactions to aspects of the center or policies and reaction to the changes or lack of them that they saw in their child. Paula, Linda and Mary had emotional reactions related to their stresses in the program but also had positive emotions related to the progress their children made in the program. For example,

Paula:

> She explained that this is not a program that ends when we walk out the door. She took me through the homework – about 15 exercises that need to be done 3-5 times each day. Holy cow. I was warned but didn't realize it would be this much. I'm trying to act calm so she doesn't think I'm a lazy mommy.
>
> It's amazing to be able to step back and measure the change; to see the new future that is Peter's.

Linda:

> I was shocked! I have never seen him complete so much work in 30 minutes! He then moved on to spend 10 minutes on his math homework. This would typically allow him to complete part of a worksheet, after about 8 minutes he came and told me that he had finished the entire sheet! This is progress and it's exciting!
>
> I feel like we're in limbo with the diet. He is doing SO good off all those foods, but his diet is so boring and repetitive, and I don't think we can sustain it for very long.
>
> I'm still glad we're doing this. It's a ton of work for me, and it's overwhelming with all that we have going on in our life, but I do think these are things that needed to happen for Luke.
>
> I was happy to have him back to feeling that way, but scared that he was going to be on this very restricted diet forever!!! It freaks me out a bit because we can't maintain this grocery bill any longer, and, it's just a miserable diet!
>
> ...quite shocking. I keep commenting on how proud I am and surprised, and he's

shocked to hear that he wouldn't've done these things just a few months ago - he can't understand why it would have been an anxiety trigger before.

Mary:

As we continued to do the exercises that Center 1 gave us to do for Maggie we increasingly were feeling alone and discouraged. I called BB in Center 2 back in July just to get more information about their Pre-Brain Balance program (for the severe kids who need one-on-one and are not ready for BB). I was encouraged and hopeful that they would be able to help Maggie.

Tuesday night, Shawn actually got frustrated because Maggie was soooooo uncooperative and he was tired. I was so discouraged and was in utter despair.

We are still so elated! If Maggie keeps up this pace, she will be ready for the harder sensory-motor exercises in no time!"

Just today I was feeling burned out and stressed/worried and was sharing it with Shawn and crying tears in front of Maggie while doing her exercises. I was shocked and I looked over at Shawn and saw the same look in his eyes that I saw when the girls were born...pure joy. Then I cried some more...and I'm still crying.... This is huge, folks! (Reaction to Maggie comforting her and noticing her tears)

After the doctor visit I was overjoyed. I had no stress in my chest no stabbing pain in my neck from the anxiety no worries at all. I couldn't believe I just took my three girls to a doctor's office with no issues!! After that we went to the duck pond and Walmart. When I was in Walmart I just walked where I needed to walk and Maggie followed me. Sometimes, I didn't look back to make sure she was there. I felt no stress. I felt no staring eyes. I felt no pain.

Brenda, Anne and George's postings highlighted that some parents had more negative experiences with Brain Balance and as a result had strong negative reactions to the program's effects on their children. In the following posts Brenda was insulted by the program and annoyed. Anne was heartbroken by the results and George was startled and angered by the claims Brain Balance makes.

Brenda:

According to the author (IMO) since my child didn't improve using his theories it is my fault because I'm obviously a poor parent. This sort of arrogance annoys me but is all too common in treating autism.

Anne:

You cannot imagine our heartbreak. This has been a year since the unfortunate experience and I am still awestruck that this program continues.

George:

I was somewhat startled to read...

I have not waited and twiddled my thumbs while my son developed.

Parents with children with disabilities will typically have a strong emotional reaction to Brain Balance because there is so much at stake for their children and themselves. Interventions that make claims about helping their child will get parental attention and elicit a reaction. The reaction is often emotional because the idea of helping their child is connected to one of their most desired needs or hopes. All the parents in the study had strong emotional reactions even the one parent who had not put his child through the program. George was challenged by Brain Balances claims to make sense of what he was doing to assist his child. Their claims shocked him and made him do an inventory of what he had done for his child. The other parents who had participated in the program experienced ups and downs of emotions during the process of the program but the most salient emotions were linked to parents' perception of how Brain Balance changed their child or failed to bring change. Mary went from despair to being overjoyed and free from emotional pain she had been burdened with. On the other hand, Anne continued to be heartbroken about the experience and it not helping her child as desired. The parents' emotions that were poured out in their online postings normalize the range of emotions a parent has when taking their child through an intervention and speak to the dedication these parents have to their children.

4.4.2 Child's emotional or behavioral reaction. Similarly to parents, the children involved in the program also had emotional or behavioral reactions to the program. Behavioral reactions often involved an emotional component that could be inferred from the behavior. An example of this was evident in Mary's description of Maggie's reaction to aspects of the program. The following shares some of the emotional reactions of the children that the parents noted in their document.

Paula:

I reminded Peter that if he didn't do the exercises as often as they recommend we might have to do more than twelve weeks. He looked at me with surprise:

We stop after twelve weeks?
That's the plan.
But I like it there.
You do?

Yup. It's fun and I like the stars.
I love that you like going.
Crazy. I never imagined that he would actually like being pushed so hard.

No problem, mom. I told you milk was bad for me.
You were so right. But dairy means more than just milk. And I go through the list of things that he will miss. He's handling it OK. Until I tell him that Fro Yo (Frozen Yogurt) is on the list.
No way, mom. I know my body, mom. They don't. Fro Yo is good. I like it. That's not the problem. Milk is. Not Fro Yo. They don't know me. I know me.
And then the tears start.

Linda:

Each time he tries something he's even surprised that he either likes it, or isn't completely grossed out by it. (eating different kinds of foods)

He enjoys it, but got bumped up a level in several things and is struggling with them, which really stresses him out. He worries what the teachers/therapists will think of Him.

Luke's been missing a lot of school this month from illness, fatigue and tummy troubles. This is stressing me out quite a bit because he is falling behind at school, which is irritating the teacher, which is giving Luke anxiety, which stresses me out more, and on goes the cycle. This school has been incredibly supportive of Luke and his needs and issues, and promised to continue to be as we went through Brain Balance, but I think that the realities of the program and it's effects on his school experience are not being tolerated too well. The old "you'll have to miss recess until you catch up" card is being played - the one that parents of "normal" kids see as perfectly acceptable, and the one that parents of "learning challenged/spectrum kids" become irate over. Let's take a kid, who has trouble focusing and experiences anxiety all day, and take away his one mid-day shot at resetting his emotions and getting some fresh air, and see how well he performs the whole second half of the day. And then, send him home to his family all worked up to do a couple more hours of homework - genius.

...he's shocked to hear that he wouldn't've done these things just a few months ago - he can't understand why it would have been an anxiety trigger before.

Mary:

...her initial assessment with the Pre-Brain Balance team in Center 2. She gave them hell to say the least. She hasn't acted so bad in such a long time. I wonder if she knows or senses more than we think she does.
Monday was hard because she did not cooperate at all. Older brother and I had to muscle her through every required movement of every exercise.

> Thursday night was the highlight of the first week of exercises. We did the Snow Angel with Maggie and she was completely cooperative! “We gave her a break and she immediately got down on the floor and started doing the Snow Angel herself!
>
> She fights and whines and acts like any kid that is fearful of something, but eventually, she picks the tablet up and puts it in her mouth and swallows it. She gags but it goes down.

The children were challenged by aspects of the program yet also enjoyed or experienced success with aspects of the program. Peter was upset by some of his diet restrictions but found enjoyment from other aspects of the program. Maggie showed her dislike of parts of the program through her nonverbal reactions but also became cooperative, even enjoying an exercise or the attention enough to do the exercise herself. These examples show that both challenges from the program and gains by children naturally resulted in an emotional reaction.

4.4.3 Changes in lifestyle. The documents also highlighted that an impact of the program was lifestyle changes for many families. These lifestyle changes meant temporary modifications in how the family functioned or meant more long-term changes in aspects of the family’s life. The documents reflected changes in the families eating habits, changes in grocery shopping, changes in activities and changes in how they managed their time. Also, for Mary’s family they also had to temporarily divide the family up into two households to access to the program.

Paula:

> It was a huge commitment and now I'm trying to remember what used to go on in our lives before it took over.
>
> As much of a hassle as it’s been for me to drive, nag and skip our frozen yogurt dates, he’s been the one doing all the work. He’s given up countless hours of video games; stopped drinking milk; listened to the craziest music ever; sat in the back seat of my car for hours each week driving back and forth; worked his hardest in all his sessions; and most of all allowed himself to be pushed out of his comfort zone.

Linda:

> I have noticed that between the strict diet rules and the food journal, we are making more consciously healthy choices, and it was evident as I did my grocery shopping tonight too.
>
> We looove our summers - we tend to fill them with activities like swim team, tennis, day trips, etc. but we also like to sleep in sometimes, and be

> spontaneous, have lazy days, and not have a list of things that HAVE to get done. But doing Brain Balance during the summer doesn't fit that lifestyle too well. I would still much rather do the bulk of the Brain Balance session in the summer, rather than during school, but it's hard

Mary:

> We have decided that Lord willing the girls and I will move to Center 2 in March and Shawn will stay here with older brother as he has to work and older brother is in highschool now. With this decision comes a domino-effect of things that have to be taken care of before we leave. We have to get ready to hopefully lease-purchase our house because we would lose too much money if we sold it. We have to find housing down there. Shawn and older brother will hopefully be able to move closer to older brother's school to make things a little easier on both of them. We have to do all the things that the BB has instructed us to do in the meantime because getting Maggie that much ahead could prevent us from having to stay there so long.
> Shawn is leaving Monday. I don't know when he will be back.
>
> We're here! Still settling in...still things that need a home, still getting adapted to apartment living (no screaming and yelling, no stomping through the house, etc).

Impacts to the families' lifestyle were a common consequence of doing Brain Balance. Changes in shopping, cooking, eating, leisure activities, and living arrangements were all lifestyle changes these families experienced.

4.4.4 Impacts on relationships. Additionally, the relationships in the family were impacted by doing the program. This theme reflects that doing the program resulted in causing changes to family relationships either temporarily to support the program participation or more long-term because of changes in the child's functioning. Relationships that were effected included the spousal relationship, sibling relationships and in some cases relationships with grandparents. The following quotes reflect the impacts on the family relationships of those who did the program.

Paula:

> ...he would have been so distracted by all of this that he wouldn't have been present with us. It would have been a very different - less fun - night. I've always suspected that we didn't have all of Peter and I was right. I'm so glad the rest of him has finally joined our family. It's where he belongs.

> Not surprisingly, they've been the cause of a few spats between Paul and me. Even though Brain Balance is my thing and the kids are mostly my job, it would be heavenly if Paul initiated the work more. Once or twice each weekend he does the exercises. But it's always at my suggestion. And then they BOTH growl at me. Because neither wants to be interrupted. I get it but they have to be done. As with everything, Paul and I recover but I cannot wait to stop being the annoying one who breaks up all the fun.

Linda:

> I wasn't counting on sister being a complete pain-in-the-butt while we did the exercises, which she was, so we'll have to get a handle on that.
>
> My mom came and got sister, brother and brother and got them all to their weight lifting and swim lessons so that I could take Luke to Brain Balance.

Mary:

> Shawn is trying to work and sell real estate as always, but having to help me with exercises and general taking care of the girls as well. We have our spats, but we are drawing closer together through this struggle (during Pre-Brain Balance)
>
> They (Mary's parents) are givers. Currently, I and my children are takers. Particularly, we take from them emotionally, but they love us still. They celebrate every minor Maggie victory with us and they feel every down as well. They are patient with sister through her difficult age and over-reactions and constant babbling. They are gracious with me when I say things I shouldn't say to blow off steam. To use a phrase that has been used many times but is so applicable, they are like fine wine...they truly get better with age. We are so blessed to have them in our lives.
>
> Still really missing Shawn this week.
>
> Maggie loves me now, Mommy!" That's what sister said today. Sister has always naturally looked up to Maggie and wanted to play with Maggie. It has been so heartbreaking to watch Maggie these past few years completely ignore Sister, her little sister. In fact, when sister came around Maggie would leave. Sister is little and unpredictable and hyper so I understand that. Here's Maggie hugging sister today...melted my heart!! As you can see in Maggie's eyes, there is no anxiety, she is really hugging sister and not just appeasing us

Because the program was so intensive and demanding of support from the family it was bound to impact the relationship dynamics of family members. Additionally, changes in the child during the program also changed family relationships. This is highlighted by the quote from Maggie's little sister where there was a new connection for the first time.

4.4.5 Effects on use of standard therapies. Doing Brain Balance changed what therapies families used during and after the treatment. The parents had a history of seeking treatments for their children and most already had their child connected to supports/therapies. When they entered into Brain Balance they had to decide what to do with their other therapies. Additionally, after the program they had to decide if their child needed any further supports or therapies. Linda and Mary commented on this issue in their blogs. Also, George made critical comments about Brain Balances place in relation to other therapies.

Paula:

> ...we have decided to take a break from all other services - OT, his social skills group and language therapy. He will continue receiving the in school support guaranteed by his IEP. He's a little freaked out about having to go so often but is beyond psyched to get a break from the rest. I was nervous about his therapist's reactions - would they feel threatened or be mad? Will they make space for Peter when he's ready to come back? To my relief, they seemed excited and are looking forward to hearing about his experience. And I guess we'll cross the bridge of whether or not they'll make space for Peter's return when we get there. Who knows, maybe he won't need to go back...oops, there I go again saying out loud what should stay in my head!
>
> I will say that the meds do help and he definitely benefits from them, but seeing him off them also let's me see that as he gets older he might do fine without them (and I am saying this w/o any medical degree whatsoever:). His focus struggle is different than it was just 2 yrs ago. He was able to do his work on his own, complete it with just a quick refocus and did follow directions. He does better on the meds and for now, "if it ain't broke don't fix it" but I wouldn't be surprised if this was not a lifelong thing." (Teacher's comment)

Linda:

> If you have a child with issues like Luke's, for many of us parents, there is a mental list in your head of "what I'll try next.". When I was checking referrences for Brain Balance, many of the parents mentioned what they were trying now, after Brain Balance, and I remember it striking me as odd, because I had such high hopes that it would be the end-all of treatments. But, I find myself making the "what I'll try next list," none the less. On it, we will be continuing the physical fitness part with a personal trainer educated in using exercise as medicine, specifically for AD/HD, the Bax Aura allergy treatments, and, if needed (we'll know when school starts) a tutor.

Mary:

> Maggie has been on the CES Waiver (Funding for services for autism) in some place USA for a few years. The past couple of years we used it heavily. She was able to do hippotherapy (therapeutic horseback riding) with The Right Step (highly recommend them), respite care, behavioral therapy including ABA. They bought her a swing set and

> a tandem bike and platform swings, etc. It has been a benefit in helping Maggie and us cope with her issues from day to day. The other day it was time for our annual meeting with Other Therapy. This is the meeting where we go through all of Maggie's issues and document them in order to plan the next year. It is always very painful for me to sit down and have to look at each and every thing that she is or isn't doing that she is or isn't suppose to do if she were neurotypical. Shawn and I have been talking off and on lately about forfeiting the services and we have come to that decision. Forfeiting the services that the CES Waiver provided is a huge step.

Although George did not put his son in Brain Balance, his comments reflected the issue of parents having to make decisions about what therapy to pursue for their child.

George:

> I want to see reviews by credible authorities before I gamble my son's development, and possibly his well being, on "revolutionary" treatments.

This theme on effects on the use of standard therapies reflects an essential question parents seek to answer – that is deciding on what approach to use to help their child. When entering Brain Balance the parents generally put other therapies on hold. Those who got positive gains from Brain Balance did not return to their past schedule of therapy but instead modified it based on the results obtained. Mary forfeited the funding she had for autism services, including a behavioral therapist. Linda was going to continue the supports that were similar to the Brain Balance program such as an exercise coach, diet/allergy treatment and possibly tutoring if still needed. Paula is entertaining the possibility that her son will not necessarily need to stay on medication for the long term. George refused to consider the Brain Balance approach without endorsement from the professional authorities. These parents' reactions indicate that standard therapies can be challenged by parents' experience of benefit from an experimental therapy. Some parents were willing to make a judgement on what therapy to use by their own trial runs and others wait for authorities to evaluate and recommend.

4.4.6 Child's changes in functioning. One of the most prominent themes that the parents wrote about was changes in the child during the course of treatment. These changes listed by Paula, Linda and Mary depicted improvements in their child's functioning or a reduction in symptoms that were giving them difficulty. In Anne and Brenda's postings the change depicted in their children was either regression or no significant/satisfying change. It appears from this small sample of parental report that there are wide variations in children's reaction to Brain Balance; with some children making significant gains, others getting subtler results and still

others having regressions (doing more poorly) or not getting results hoped for. The following examples discuss the changes in their children in the parents own words:

Paula:

> It's amazing to be able to step back and measure the change; to see the new future that is Peter's. I forgot how sad Peter was. And what a challenge every new experience was for him. And how hard it was to watch. But now his story is different and we've rewritten the rest of the chapters. Outstanding in every way.
>
> In addition to being blown away by his strength and pliability, I cannot get over the strides Peter is making in school. There are all the social leaps that just keep coming one after the other – saying happy belated Mother's Day to Mrs. Teacher unprompted on Monday, starting up a relevant chat with an old teacher who says he didn't initiate a conversation ever in the whole year she taught him, loving playing Four Square, making new friends, the list goes on and on. And now, we're starting to see cognitive improvements too. He has always been a solid reader. He learned early and enjoys books. What held him back on testing was his comprehension. But now, it's starting to soar. He can actually process what he's reading and according to testing done this week, he is somewhere in the 4th – 5th grade reading level. What's even more exciting is that he's more comfortable talking about what he knows. Here's a snippet from today's Mrs. Teacher email:
>
> > I read with him again today and it is so much more than just his comprehension. Not only am I not prompting him; he goes on in detail and answers smoothly and completely. He uses the characters names more than not. I know that sounds strange, but he used to have more trouble finding the words and his answers came out in more of a choppy way.
>
> And there's growth outside of school too. On Wednesday, he had his first class with a Fitness Trainer in town named Trainer. Peter signed up for semi-private lessons with his friend Larry who is equally klutzy and uncoordinated. The class was an hour. They jumped rope. They skipped. They had so much fun. It was hard but they all laughed a lot and struggled through. Afterwards, instead of wanting to run to his one hour of video games, he opted for a play date at Larry's. When I finally got him home, he didn't want to go inside. Instead he asked to play basketball in the driveway. By now you know, this is atypical and a very welcome deviation from his norm.

Linda:

> Luke is processing complex ideas when have discussions. He's following sarcasm and inferences better, and is requiring a lot less explanation to understand things. I find myself smiling to myself mid-conversation with him when I realize I didn't have to stop to explain something to him, and instead he's laughing along with me or adding to the idea. It feels like a relief.
>
> In regards to those observations: I've noticed the hyper activity - it's not

quite as annoying as it's been in the past, but more entertaining, but definitely there. He also seems happier to me. He seems calm and better able to control his emotions - things that would usually send him into tears, aren't. In the recent past, anytime he was awake past 10pm would ALWAYS amount to crying and anxiety, it was completely predictable - we're not seeing that anymore. He is still crying from time to time, but it's less often, and he's easier to console. As far as his skin rash, I've only noticed it being worse on his arms - the nutritionist said that sometimes there is a purging of toxins at the beginning of an elimination diet, which can show up as worse symptoms before they get better. I've noticed he looks a little thinner in his face and body. I think that he's standing with better posture, which is making him look taller and thinner (because his belly is held back when he doesn't allow his back to arch with it's huge sway). I also think that his face and body look thinner because he's not bloated - when I think to his body before Brain Balance, sometimes he just had a bloated look. Maybe the food allergens being eliminated has helped with this.

I am really enjoying my conversations with Luke, and helping him with his homework. He and I are able to joke back and forth, and he is using and understanding sarcasm for the first time (a fluent language in our home). He's also understanding discussions about homework topics much faster now too. This shows me that his processing speed is picking up.

A really exciting show of progress came on Friday at his Field Day. Luke LOVES field day, and looks forward to it every year. But every year, it ends up being a challenging day for him - physically and emotionally. At his old school, there was a big focus on 1st, 2nd and 3rd places, and Luke always wanted so badly to place in the events - but it was hard for him - he's just not been very athletically inclined for so many years. A few events into the day he would usually come to me crying or fighting back tears, disappointed in his performance, and worried that he wasn't going to get any ribbons by the end of the day. At his new school, he was still upset with himself last year during the day. But this year was very different. Not only was he keeping a very close pace with the most athletic kids in his class, he wasn't worrying about his performance. He didn't cry or tear up all day. He never came to talk to me about how he was doing other than to tell me how GOOD he was doing. In fact, he hardly acknowledged me all day!! One of the most enjoyable times for me was when the kids had a rotation at "Black Top Games." They could play with all the things that were set out - volleyball, tether ball, 4 square, jump rope, hula hoop, etc. He chose to do jump rope. Luke hates to jump rope. But on Friday he picked up the jump rope and ran back and forth jumping rope, circling around his friends while they talked, and jumping in place. He has never known how to jump rope. He came close to me and said "You know what I figured out? There's a rhythm, and if you get the rope going to a beat, you're body just knows what to do." It was an awesome moment.

Mary:

I was so discouraged and just missing Older Brother and feeling guilty and feeling sad because Maggie seemed to be regressing in certain areas (which we were told that she would...however, I suppose I thought it would be different for us...ha). Attentively and adoringly, Maggie sat up and looked at me with her sweet eyes and smiled. "Kiss", she said, and then crawled over, wrapped her arms around me and and hugged and kissed me and said, "I love you" and then kissed me again and said, "I love you" and then again and again. I was shocked and I looked over at Shawn and saw the same look in his eyes that I saw when the girls were born...pure joy. Then I cried some more...and I'm still crying.... This is huge, folks! She has never shown empathy at all in her entire life. She has never expressed two hoots when anyone is down or hurt or crying!

Maggie followed us right in the office, sat down and started looking at a bird book and looked out the window and was so calm and so well-behaved while the doc and I talked. Sister was also very well-behaved and did not interrupt us every minute. We had to go into another room to weigh Baby and Maggie didn't follow us but I heard her say, "Mom...Mom..." and then I heard one of the nurses say, "Mom's in here, honey. Go in there." After the visit, Maggie walked out and sat in the waiting room and watched the fish without trying to reach in and catch one and without climbing on the tables and jumping off and without running out the door into the parking lot without me! She just sat there like a normal child waiting on her mother to pay the bill.

Brain Balance has given me the confidence to go out in public without that stabbing pain in my neck and shoulders because of the stress and anticipation of stress. We don't need respite care anymore. I actually enjoy going out with my children (most of the time). We don't need a behavioral therapist anymore. I used to make jokes with Shawn about how I felt like I was in prison and the warden Maggie decided when I got to eat, go to the bathroom, cook dinner, go get my hair cut, etc. If I could work the care of Maggie out then I could do this or that. It was usually so much trouble that I would just put off going to the grocery store until we just didn't have anything to eat or put off getting my hair done or things of the sort.

-- She is using more and more language everyday.
-- She is not as fearful of the essential oils and other strong fragrances that we are trying to get her to smell (ultimately closing her left nostril and smelling through her right)and in fact picked up one of the cotton balls and smelled it herself.
-- She is being very playful with Sister and the past couple of days Sister has actually helped with some of her exercises and did some with her.
-- She is calmer when go out to eat and other places where there is lots of noise and people.
-- She is consistently mimicking our facial expressions.
-- Overall, she is still Maggie but a much happier and more socially engaged Maggie

Brenda:

> My child went through the Brain Balance Center program 3 times. Unfortunately during and after the program my son's regression has caused him to get less time in a general education classroom and more time in the spec. ed. Classroom.

Anne:

> At the end of our 12 weeks, BB said 'oh, we've made progress but not enough...

It is apparent that three of these parents felt significant and positive changes resulted from the program, while two parents did not. As a result, the theme of the child's changes in functioning while in Brain Balance stimulates many questions for further research.

4.4.7 Financial cost. Financial cost was apparent in many of the documents and conveyed how the cost of the program affected the families. Of course for each family this was dependent on context, as it was more of a sacrifice for some than others; yet for all families it was a significant impact of doing the program as it was not covered by insurance. Paula, Linda, Mary and Anne all reflected on the financial cost of the program.

Paula:

> I also worry that it's hype and in four month, we will be in the same place we are today, just with less money and slightly broken hearts.

Linda:

> For 90 days of multi vitamin, and 30 days of amino acids, the cost was $364! But we will use them until gone and should then be able to move to an over the counter version or both
>
> The cost of Brain Balance, if you are considering doing it, goes far beyond the $6000 for the session (12 weeks of therapy, 3 days per week, including a reevaluation, 5 nutrition consults, progress reports).I don't generally feel comfortable publicly discussing our finances, and I know that we are (if silently) being judged by some of those who read this, but I want to be completely honest in this blog for the benefit of other families in our position:
>
> initial evaluation = $75 (usually apx $250, we used a coupon)
> 1 session = $6005
> blood/urine tests (if not covered by insurance) = $495
> lab blood-draw fee for above test = $46.29
> gas bill = apx $90/mo.
> grocery bill for elimination diet = $600/mo
> supplements personalize based on lab results = $384.45 (one time purchase)
>
> half way through the program = $7540.74

> anticipated cost by the end of 12 weeks (and through the end of the reintroduction period which may go beyond the 12 weeks) = $9126
>
> We will have to continue spending on gas for the next 6 weeks, and groceries until the end of the elimination diet (some diet changes will be permanent). Some families have to do another 1/2-full session ($3000-$6000).We also still have to purchase digestive enzymes once he starts the reintroduction stage of the elimination diet, not sure how much those will cost.
>
> My feeling about these numbers: We financed the $6000 over 5 years, so we pay only $128/mo - in my mind I equate that to paying for something like braces. It is painful to spend the money, but it is worth it to us.

Mary:

> We have to come up with the money to pay for BB. We think we have about one-third of the money so far, but we are considering some fundraisers. We have to find some help for me down there because the program is only 3 hours/week and then we have a home-program that covers the rest which falls on me.

Anne:

> There were promises by the director of music cds, books and help post session. In the end, our family was out $5K. When the program completed, we were told, "we'd love to continue to work with your child-but we will need another $3K to continue."
>
> I wouldn't have cared on the amount of money we spent on trying to find a non-medicated based therapy for our child. I do care that they only saw our family, our child, as a profit margin.

In this theme the parents conveyed that the cost was high and they had to find ways to adapt to it. They all seemed ready to pay if the results were worth it. It is evident that this indicates that parents being willing to do all they can for their child made them vulnerable to financial exploitation. This is a matter to seriously ponder in terms of regulation and research; yet people do have the right to take informed risks.

4.5 What Motivates Parents to do Brain Balance?

Analysis of the three main blogs about doing the program generated four themes that related to motivation. All three parents conveyed two themes: Seeking Meaningful Gains in Child's Functioning and Disappointment with Results of Previous Treatments. A third theme found in Paula and Linda's blogs was Following Others Success with Brain Balance. Finally, a fourth theme was conveyed in Linda and Mary's blogs Child's Symptoms Need Treatment.

4.5.1 Seeking meaningful gains in child's functioning. All three parents were mainly motivated by seeking meaningful change in their child's functioning. Seeking meaningful change meant that the parents were seeking a change that reduced symptoms so that the best possible functioning for their child was achieved. This was referred to as being either "a typical life", "levelling the playing field" or "finding a cure". The specific changes sought by parents varied. Paula, Linda and Mary all wrote of having hope that the program would help their child improve in functioning.

Paula:

> ...giving him access to the best life possible fits right into the rules listed in the mommy handbook. No doubt about it.
>
> We all want to do whatever we can to provide an advantage - or at least remove the disadvantage - for our child. Whether you "red card" your son with a September birthday so that he's the oldest in his class, or hire a tutor, or send her to soccer camp in the off-season or take him to Brain Balance - all level the playing field and may even give your child the upper hand. And in my book, this is a good thing.

Linda:

> It is my dream that he is able to sit down and complete his homework with little assistance, in about an hour. I hope, hope, hope this is a step in that direction
>
> ...watching my son struggle all these years, the chance at an easier life for him is worth it. If it gives us the results we are hoping for, I will definitely say it's been worth it. If it falls short, there have at least been some successes, and we will end up chalking it up to something we had to try, to see if it could work.
>
> The areas I'm hoping to see the most improvement in this program would be: school, athletics, self- management at home, improving feeding issues.

Mary:

> I want so bad for Maggie to stop picking her face and causing scars. I want so bad for her to read me a story instead of endlessly coloring shoebox tops. I want her to have friends. I long for this everyday.
>
> I can't wait to post a picture of Maggie eating an ice cream cone. I know she wants to but she just can't do it.
>
> If God heals Maggie through Brain Balance or any other means, we will rejoice until the day we die. If God chooses to keep her the way that she is, I know He will provide the daily bread/grace that we need to love her, teach her, and show her and our other children His glory today and every day.
>
> Let's face it, when one child is "lost", we as parents are like the

shepherd who leaves the 99 and goes to rescue the lost one. Even when I am engaging with the other children, I grieve for Maggie.

One of my dreams as well as every mother's dream is for my children to love each other. I want them to be friends when they are old. I want them to learn to be gracious and forgiving toward each other while they are young. Maggie's Autism has definitely changed how we deal with sibling relationships in our home. What are we suppose to tell sister when she says, "Maggie won't play with me. Maggie doesn't love me. Maggie's mean. I wish we could give Maggie away. All of these statements communicate sister's pain and frustration.

4.5.2 Disappointment with results of previous treatment. The parents had the sense that previous or current treatments did not produce hoped for change or were only managing the problem symptoms. The parents all conveyed this in their own way in relation to their specific context. The parents were obviously hoping for more gains or were impatient with the other treatment.

Paula:

...despite years of therapy, evaluations, IEPs and countless miles on our car, he's not improving as quickly as we'd like so we're ready to try something new.

For these, he sees a psychologist, a psychiatrist and is part of a social skills group. And because he has a hard time deciphering lengthy directions or conversations, he just recently started language therapy (a variation of speech therapy). Thanks to all of this, Peter has made some major strides forward. I'm proud of the work he's done and I appreciate how easy he makes it to shuttle him from one appointment to the next. But I am always on the lookout for a new cure or treatment

Linda:

He began therapy at a feeding clinic at Children's Hospital. He went once a week. We had to joint compressions and brushing at home to help his Sensory Integration. We did an entire summer of therapy and saw little to no improvements.

Luke is making so much progress on his own but he still also has so many symptoms that need addressed.

Mary:

I had to fill out an assessment for Maggie's behavioral therapy services. I went into the pit. I had to think in detail as I do every six months about all the many things that she is not capable of doing. I just couldn't handle it.

We have put her in so many therapies/programs. Everything has helped a little, but nothing has given her remarkable progress.

At this stage in supporting their children these parents had been through all the standard approaches and acknowledged some progress or at least accepted that it helped to manage the symptoms of their child, yet they all conveyed some disappointment with the results by trying to seek a better solution.

4.5.3 Following others successes with Brain Balance. Parents felt encouraged to try the program because of others with a similar diagnosis had success with the program. Both Paula and Linda's blogs conveyed this theme as part of what motivated them to try Brain Balance. The influence of a parent in Paula's community really impressed her and gave more credibility to the program. Paula and Linda's comments follow:

Paula:

> ...last October, when I heard about Brain Balance from a mother in town who has a kid with ADHD, I was on a mission to learn more about it. Betty Q is a mom at Peter's school and I have known her for the past year. Not well. But we both helped out at last year's book fair and I've seen her around. She has a nice way about her and when I heard she opened up a new business that caters to kids like Peter, I felt comfortable sending her an email asking what it was all about. She responded quickly and invited me in for a tour the next day.... She shared the story of how she got hooked up with Brain Balance; I am envious of her son's results. I want to be in her shoes and I am immediately sold - not by the facility but by Betty's passion. I want what she's selling and I want it now.

Linda:

> Families who are sacrificing to put their children through this program are seeing miraculous results- autistic kids are "waking up" in 3 months time, AD/HD kids are coming off medication in 3 months time!!!
>
> One of the moms I talked to for a reference said that her personal stress level has gone down so much since her son completed the program - she never realized what a burden his issues were to her happiness and everyday functioning until now. She said their life is so much better and that the saddest part is what she feels are all the "lost years" before Brain Balance when life wasn't what it could have been for her son. I'm glad we're doing this now. I'm glad we didn't wait.

Clearly, both Linda and Paula were motivated by the success these other families experienced from the program. One of the children was in the community for Paula to witness and the family that talked to Linda had nothing to gain but shared their testimonial. Thus, some parents were influenced by others experiences with the program.

4.5.4 Child's symptoms need treatment. A child's symptoms needing treatment underscored the daily reality of these families trying to find effective ways of supporting their child. It was clear that Paula, Linda and Mary were simply seeking a way to deal with symptoms by trying the program.

Paula:

> Having PDDNOS (pervasive development disorder not otherwise specified) means that Peter has lots of symptoms that don't add up to official autism but he's definitely somewhere on the spectrum. We knew something was off when he was just under a year old. He rolled over, crawled and cruised on time but then his development stalled. He didn't talk at all. He didn't understand anything we said. He worked with Early Intervention for a while and then moved on to private speech therapy, private OT and private PT.
>
> Eventually, he learned how to talk, walk, run and jump. Now he can do it all – he just can't do it with the ease most others do. He's still floppy with low muscle tone. His fine and gross motor skills are not where they should be. He makes great eye contact but takes a while to warm up.
>
> In addition to the physical stuff, he has mild depression, anxiety and ADD.

Linda:

> He has AD/HD- inattentive type (which means he is non-hyper), anxiety, slow processing (unknown cause) He is very smart, but struggles to produce quality schoolwork or test taking. He needs laborious amounts of assistance and instruction to complete the most basic daily tasks and assignments
>
> I've been seeking help for him and looking at every option and explanation, and I've come across all kinds of viewpoints and approaches.
>
> ...Were his usual tics – the shoulder scrunching, the hip bumping with his wrist (Linda was observing her sons motor tics prior to the program)

Mary:

> ... feel pain when I walk through the store and hear a Mom and daughter having a conversation about the daughter's day at school and her friends? Should I not allow myself to weep because I want that? I long to have that very same "trivial" conversation with my sweet Maggie.
>
> It is really stressful to go most places with Maggie alone...add sister and it's double...add a baby and it's triple...minus older brother and it's exponential! So, my initial thought was that if God healed Maggie then I would be able to take everyone out to the park or the zoo or the grocery store; otherwise, it could be hazardous to our health!
>
> She is very disengaged these days. She is in her own world,

> making colorful plastic shoebox tops her obsession. I admit that I am very depressed. Sometimes, I think I don't want to live if I have to watch my child "die". But I keep hoping...

Because the program claimed to assist children with a range of symptoms it had a wide appeal. Thus, three very different children Peter, Luke and Maggie were seen by their parents as possibly benefiting from the program. The programs claims were to reduce the symptoms of their child's disorder and this was exactly what motivated the parents to try the program.

4.6 What Motivates Parents to Write About the Experience Online?

The question of what motivated parents to write online about their experience with Brain Balance gave diverse results. All six documents contained information pertinent to this question. The three detailed blogs of parents having done the program shared two common themes (1) Documentation and (2) Sharing Information to Help Other Parents. Additionally, Mary and Linda showed motivation that fell under the theme of (3) Communication with Personal Circle. The parents who posted shorter critical postings also exhibited motivation for writing online. The two parents Anne and Brenda whose children had gone through the program posted online with the motivation consistent with theme (2) Sharing Information to Help Other Parents. Finally, George's critical post regarding Brain Balance fell under two themes unique to his posting, these being (4) Dialogue with Stakeholders and (5) Stimulating Change/Advocacy.

4.6.1 Documentation. This theme of documentation was about the parents keeping track of what was happening while they were doing the program. They were using the online writing as a journal or diary of events. Paula, Linda and Mary explicitly stated documentation as one of their motives for writing online as evident in the following quotes:

Paula:

> Then why am I doing it? I am about to embark on what I am hoping will be a memorable journey with my son. I want to be hyper-aware of any changes that take place.

Linda:

> I am starting this blog for the main purpose of documenting our family's journey through the Brain Balance and Bax Laser Allergy Treatment programs with our 11-year-old son. I want to remember it,

Mary:

> The purpose of this blog is to loosely document Maggie's Brain Balance program.

4.6.2 Sharing information to help other parents. Another prominent theme for writing online was sharing information to help other parents. The parents they were trying to help were other parents with children with similar difficulties as their own. They all had been in the position of making decisions on treatment and seemed to want to add to the information related to this program in case it could help someone else. At times in their blogs they were directly talking to these parents. While Anne in her shorter postings was posting on a forum in which other parents were discussing Brain Balance. The parents seemed largely motivated to share their story to help other parents.

Paula:

> I don't know how many details you really want to hear about my kid, and I don't want to be a super braggy mom, but I hope this information will be useful and provide a sense of what you too can expect for your son
>
> So if you've been reading this blog from the beginning, you probably think that I believe in Brain Balance. That I trust them and I think that they know what they are doing. but as of last night things changed. I am a true believer.

Linda:

> I want other families with spectrum kids who need "proof" to come across our blog and be inspired.
>
> It pains me to make the negative statements about the program and the individuals, but again, I'm trying to be honest, and to put a voice to my thoughts for those who are considering the program.
>
> I want to be completely honest in this blog for the benefit of other families in our position

Mary:

> These are my thoughts, not all of my thoughts because I won't be imprudent, but what I write will reflect what I am thinking or feeling at the moment that I write it.
>
> For you bottomliners, here the skinny for this week:
> -- I'm currently doing Maggie's exercises by myself and she is cooperating minus a few silly moments. ...(Mary talking directly to readers about Maggie's gains)

Anne:

> Do NOT go to Brain Balance! We were one of the unfortunate families to have thought this program would have helped our 9yo child.
>
> I recommend you contact a great psychiatrist specializing in ADD/ADHD.

These quotes demonstrated the audience these parents were addressing when they posted online. They were speaking directly to other families with the intent of trying to be helpful in sharing their story.

4.6.3 Communication with personal circle. A theme unique to Linda and Mary's documents, although common on some media on the internet, was communication with their personal circle. This theme is apparent in the documents as a motivation to write online when it is evident that the bloggers are communicating directly with people they know. Linda seemed to want to let people in her personal circle know what they were going through and blogging was an efficient way to do so. Similarly, Mary used her blog to thank those who supported their efforts and to ask for support from them. The quotes below show this theme explicitly.

Linda:

> I want our family and friends to understand what we're doing

Mary:

> Please pray for Maggie especially that she will be as calm as possible so that they won't have to use much restraint.
>
> Thank you all for your prayers and words of encouragement and tears of joy that you have shed for and with us this week! We love you, friends!
>
> Thank you, God! And thank you, my sweet friends and family, for praying for us!
>
> ...when I am struggling through my daily life with Maggie, I ask for grace from you. I ask that you allow me to struggle through my depression/despair, my sin of not trusting Him, my sin of anger toward Him, my Christian walk in a nutshell.

4.6.4 Dialogue with stakeholders. The theme of writing online to dialogue with stakeholders conveyed the idea of a parent using online writing to engage interested others in discussion about what is best for individuals with autism. George addressed parents specifically and responded to people who posted comments on his blog. In this way he was actively trying to engage others in dialogue to work out understandings and take a position.

George:

> I am not telling other parents what to do with their financial resources or their child's precious development time,

4.6.5 Stimulating change/advocacy. Additionally, George's postings showed the theme of stimulating change or advocacy by writing online. This meant that George was attempting to influence others to do things that were beneficial to individuals with autism.

George:

> My interest in autism, and my advocacy, began with the realization that locally at least no serious efforts were being made to improve the lives of persons with Autism or to address the realities of Autism Disorder. Hugs are good, but hugs are not enough. Evidence based treatment, education and residential care by properly trained service providers are required to help the 1 in 110 persons who have an autism spectrum disorder.
>
> I pledge to fight for the availability of effective autism treatments, ... a real education for autistic children, ... for decent residential care for autism, ... for a cure for autism, ... to continue finding joy in my son but not in the autism disorder that restricts his life... I pledge to fight for the best possible life for my son with autistic disorder.
>
> The effectiveness of ABA-based intervention in ASD's has been documented through 5 decades of research...

Overall, all the parents who posted online wrote to give something to the community of parents and children with disability. That is they seemed motivated to help advance care and treatment of these children – individually and as a group. Each parent did this by sharing their own perspective and experience. Their writing online represented their voice.

By analysing this group of voices a series of themes emerged which cluster around the research questions of this study. These themes provided a description of what it is like to do Brain Balance, what judgements parents made about the program, how parent and child are impacted by the program, what motivated the parents to enroll their child in the program and what motivated them to write about the experience online. If this collection of voices is considered, it can assist in evaluating this program, understanding the complexity of multimodal approaches, understanding the vulnerabilities of families with members in need of intervention, and has implications for future research.

CHAPTER 5: DISCUSSION

The findings of this study describe parental experiences with the multimodal program Brain Balance. The description highlights what the program was like to participate in, asserts parents judgements about the program, describes the impacts of the program on parent and child and describes parental motives for engaging in the program and writing online about it. These findings are summarized and discussed in terms of the current literature. Next, implications for research and practice generated by the findings are discussed.

5.1 Summary of Findings

The findings of this study give a detailed description of six parent's experiences with Brain Balance. These experiences included many common themes but also showed diversity in individual judgements about the impact of the program on their child. Because of a scarcity of studies on Brain Balance, these descriptive themes provide information lacking from the research literature. The online documents of these six parents' revealed themes that fall into five categories that are framed by five research questions. These are summarized and represented in relationship to the current research literature.

5.1.1 What is it like to participate in Brain Balance? It is apparent, from the three detailed online documents, that these particular parents participating in the program had six main experiences while doing the program. They proceeded through the program in stages and they did the multiple components of the program both at home and at the center. These components were as follows: (1) Home components – primitive reflex exercises, sensory-motor exercises, Brain Balance music, diet changes, supplements and lifestyle changes; (2) Center components- sensory-motor exercises, Interactive Metronome, cognitive exercises, consultations with director and nutritionist. Additionally, they encountered theory as a rationale, faced challenges implementing the program and developed means of coping, all the while looking for change in their child's functioning and debating the cause of the change. These general themes of participation may be found in many interventions, when participants' experiences are surveyed (Dennison, Stanbrook, Moss-Morris, Yardley & Chalder, 2010), but the combination of the program components and the theory behind Brain Balance caused it to be a different experience from other interventions.

The Brain Balance program is multimodal, meaning that multiple treatment methods are used to treat the disorder. This is not unique to Brain Balance as multimodal therapies have been used in the treatment of AD/HD with the modalities of medication and behavioral approaches being used (Pelham, 1999) or Multimodal Social Skills Training being conducted with cognitive behavioral and behavioral methods to address cognitive, affective and behavioral aspects of social functioning (Bauminger, 2007). In the case of Brain Balance, the modalities of intervention included nutritional, gross motor, sensory, academic and temporal processing exercises. Components of the program fell in the area of therapies provided by occupational therapists, nutritionists, special educators and psychologists. Having all these components seemed to make the program comprehensive and this played a role in attracting parents to the program. Some parents thought it was convenient to have all the things their child needed in one program. Yet, the program being multimodal made it difficult to assess what was affecting the child if a change occurred. This was evident from the common process of a parent debating what caused a change in their child's functioning. A complex research design and a challenging analysis (Pelham, 1999) would need to be constructed to answer that question. There were six areas of the home program and four different areas to the center program. The parent and child had to simultaneously do both aspects of the program. The burden of doing all aspects at once seemed to be a stressful or a challenging experience for most families forcing them to find ways of coping with this stress. The stress from the program is concerning considering that research consistently finds that parents and siblings of children with neurobehavioral disorders generally experience more stress than their typical peers (Rao & Beidel, 2009; Dabrowska & Pisula, 2010). Thus, if an intervention increases the stress of these families in an unreasonable way this could be detrimental or make a treatment less effective. The question as to the necessity of the simultaneous implementation of all aspects of this program stands out. Could not some of these components be timed to be consecutive, thus avoiding some of the stress? For an intervention to be effectively implemented the stress level of a parent must be addressed or the parent will not be able to effectively follow through on participating in their role in the therapy (Rao & Beidel, 2009). It is notable that the experiences of the parents in this study indicate that parental stress is increased because of the simultaneous implementation of the multiple modalities of Brain Balance.

Brain Balance offers a theory of what is happening in their intervention; yet this theory needs to be evaluated based on empirical research. The Brain Balance theory that parents encountered while in the program had some basis in neurological research but was oversimplified as a rationale in this program and did not always match up with what participants in the program were being asked to do. Specifically, functional disconnection can occur in various neurological based disorders (Catani & Mesulan, 2008) or as an aspect of a disorder (Epelaum et.al, 2008) and it is a term that is used in neurology but current understanding of the neural dysfunction in autism and AD/HD is more complex than the hypothesis that Brain Balance conveys to parents of a functional disconnect between the two cerebral hemispheres (Cantani & Ffytche, 2005). Rather the theory of connectivity in Autism Spectrum Disorders is characterized by local over connectivity in brain regions and long distance under connectivity between brain regions (Anderson, Druzgal, Froehlich, DuBray, Lange, Alexander, Adildskov, Nielsen, Cariello, Copperrider, Bigler & Lainhart, 2010). This is a conceptualization that in part describes a functional disconnection but also advances understanding to include over connectivity and the overgrowth of white matter (Anderson et.al, 2010). Additionally, other brain regions beyond the cortex, specifically more complex neural networks are involved than just the cerebral hemispheres in these disorders (Cantani & Fftche, 2005; Anderson et.al, 2010; Fiedorowicz et.al, 2001). Also, it is apparent that the exercises the participants were asked to do in Brain Balance were not always consistent with the theory used as a rationale. For example, Interactive Metronome is not about specifically resynchronizing the right and left cerebral hemispheres but instead is about making the parietal cortex, sub-cortical structures such as the basal ganglia and thalamus, and the brain stem structure of the cerebellum communicate more efficiently (Mauk & Buonomano, 2004). Also, the primitive reflexes are presumed to originate in the brain stem and not the cerebral hemispheres (Teitelbaum, Benton, Shah, Prince, Kelly & Teitelbaum, 2004); therefore the programs' rationale that primitive reflex exercises balance the hemispheres is dubious. Similarly the dietary and supplement changes participants go through most likely address underlying dysfunctional physiological and neurological processes (Kohlstadt, 2009; Kaluzna-Czaplinska,2011) and do not necessarily correct the exacerbation of functional disconnection between the hemispheres as Melillo proposed (Melillo, 2009). Also, academic tutoring does not just target one hemisphere of the brain to work on the weak side as Melillo proposed (Melillo, 2009) but it can focus on targeting weak skills of which multiple brain

networks are involved (Fiedorowicz et. al, 2001). Thus, the theory used in Brain Balance as a rationale was not consistent with evolving neurological understandings related to neurobehavioral disorders nor do the Brain Balance components and exercises all fit in its proposed rationale.

Nonetheless Brain Balance's theory was encountered by parents and was used to give the program a scientific sounding foundation. This is one of the aspects of Brain Balance that attracts parents but unfortunately many parents do not have the background to evaluate the theory that is proposed as a rationale for Brain Balance. If they did so they would find that it appears from other research that functional disconnection of the two hemispheres as an explanation of neurobehavioral disorders is an oversimplification (Menon, 2011), although it could be involved in some respect. Menon (2011) indicated that studies summarizing neurological disorders show evidence that these disorders have "structural and functional abnormalities in multiple brain areas involving several different brain systems"(pg. 486). Furthermore, the exercises in the program are not always targeting the alleged weaker hemisphere (Fiedorowicz et. al, 2001). Additionally, Brain Balance does not acknowledge/credit in their marketing, the use of Interactive Metronome, which is not proprietary to Brain Balance but originated elsewhere (Cassily, 1996) nor do they highlight the neural areas impacted by the use of IM. These areas include cortical, subcortical and hindbrain structures (Alpiner, 2004; Mauk & Buonomano, 2004). These inconsistencies in how Brain Balances theory connects with its exercises and with broader research make Brain Balance's theory an oversimplification used in marketing the program.

Clearly, caution in embarking on this program is warranted as the findings of this study indicate that the program is very demanding to families. If aspects of the program are relevant to a family it may be possible to pursue aspects of the intervention in a more incremental way with the guidance of relevant professional consultation. For example, see an integrative doctor or nutritionist regarding dietary treatments. Also, skepticism of how the prescribed exercises follow from Brain Balance's theoretical rationale is appropriate, as Brain Balances theory does not seem to be an accurate account of how some of the components of the program affect the brain. Further research will uncover better understandings of brain function in neurobehavioral disorders but from what is already known there is more going on than just a functional disconnect between the two hemispheres.

5.1.2 Parent's perceived judgements about Brain Balance. The parents in the study all generally made five different types of judgements about Brain Balance. For example, they had initial reactions about the program, reactions about quality of service, comparison of Brain Balance to other programs, a final judgement about doing the program and a final judgement of the programs impact on their child. The description of the judgements of these key stakeholders could contribute to an evaluation of Brain Balance (Patton, 2002). The parents shared their opinion on the value of or the degree the program met their and their child's needs; this gave the parents' statements an evaluative tone (Mertens, 2010). Furthermore their judgements contribute to a better understanding of the processes and outcomes connected to Brain Balance.

Some of the specific judgements the parents made initially about the program were that it was too expensive, it was simplistic and could be done at home. Another critical judgement about the program was that it did not have the recommendation of a credible clinical authority. Some parents, despite initial concerns, went ahead with the program. It would seem than that they did not fear any significant risks from trying the program. This finding has implications related to assisting parents in making decisions about treatment and being aware of empirically supported treatments.

Of the parents who did the program they all shared some concerns about the quality of the service that they received, although they generally appreciated how well their child was treated. Parents made comments about being given wrong or old information about how to do exercises or wrong dosage information about a supplement. Additionally, one parent experienced the center changing a policy related to reintroduction of foods on an elimination diet. She found this to be confusing and it made her question if this was a marketing decision. Some parents were aware of differences between centers in terms of what clients the particular center worked well with. Finally, one parent found a center to be disorganized in how they ran the program. All of these evaluative judgements are important in understanding how this program gets implemented and are a small sample of comments that would be necessary to evaluate a program as a way of ensuring quality.

Parents in the program also made judgements about how Brain Balance compared to other programs. One main finding here was that parents recognized that Brain Balance borrows from other approaches such as tutoring, nutritional counselling, Interactive Metronome and physical or

sensory therapy. This judgement has implications on how parents can access these therapies and how the costs are covered. That is, some of these services may be available through public institutions or be covered under insurance plans if pursued through professional recommendations/referrals. On the other hand, parents liked the convenience of having one agency oversee all therapies and the convenience of one center to go to. Finally, one parent rightly pointed out that therapies without an evidence base can waste the money and time of families that would be better spent doing something else. Thus, these judgements bring forward the issues of coordinating multiple services and the evidence base of an intervention.

The evidence base of a treatment is important for the public to consider and be informed of. Brain Balance is still considered experimental and does not have sufficient empirical evidence to be making the claims that it is making (Stelle, Elkin & Roberts, 2008). Parents may hope that this will be the end of all intervention for their child but many parents, even when they get some improvement from the program, continue with other interventions after the program. The probability of success from an intervention is related to matching up appropriate candidates with a quality implemented intervention that has been studied with a similar population. If, like Brain Balance, there are insufficient rigorous studies the intervention is still experimental and potential users should be informed of the interventions experimental nature. There may be some merit or effect from the treatment but it has not been sufficiently proven; therefore it cannot be recommended with confidence. On the other hand, an empirically supported treatment has been systematically reviewed.

Empirically supported treatments fall into two categories – well established and possibly efficacious treatments (Steele, Elkin & Roberts, 2008). Well established treatments are supported by studies from multiple independent researchers who compare a treatment to another treatment in a group design or in single-case designs. The studies' treatments are manualized and client characteristics detailed. Probably efficacious treatments have two rigorously designed studies demonstrating the treatment to be more effective than no treatment or a series of single case design experiments. All other treatments lacking this research are considered experimental. In the case of Brain Balance it does not meet the standard of empirically supported treatments. That is it is lacking studies comparing it to other treatments, lacks multiple independent researchers and it is not manualized (lacking detail to be replicated by other researchers).Users of experimental

interventions should be informed of and consider the associated risks commonly associated with them. As one parent rightly pointed out, experimental interventions can cost time and money that may have been better placed elsewhere. Yet, as this study shows some are willing to take the risks.

Parents in the study who took the risk also gave a final judgement about doing the program. A number of parents commented that the program was difficult to do. They had difficulty implementing so many things at once. One parent asserted that the program was expensive and that one could pursue a specific aspect of it that she thought was responsible for the changes in her son. Another parent warned that the outcome of the program is variable, with some getting results while others do not. Finally, a parent who did not get results from the program thought that it was ineffectual and motivated by profit. These overall judgements could be interpreted as meaning that parents perceived the Brain Balance program to be difficult, variable in results and expensive. Often these overall judgements were influenced by the parents' perception on what the final impact of the program was on their child.

The parents' views on the final impact of the program on their child were diverse, with both positive and negative views. Two parents (Paula and Linda) strongly thought that the diet/supplement component of the program made the most noticeable impact and was responsible for the changes in their child. Mary thought the program was life changing for herself and her child and she attributed the change to the program generally as well as being impressed with the primitive reflex exercises. It was interesting that when reading the changes in Maggie over the time line of Mary's blog that most of the changes she reported were most significant/noticeable after she started her child on the supplements even though she had been doing some of the exercises during the year prior at home. In other words taking the supplements seemed to correlate with the changes in her child, whereas the home exercises done during the prior year of Pre Brain Balance did not. An alternate view from Brenda and Anne about the program was that they both felt that Brain Balance did not help their child's symptoms improve significantly.

For those parents who did perceive positive change in their child it was interesting that their conclusion seemed to be consistent with what research indicates. That is research on SIT is inconclusive (Lang et.al, 2012) therefore it is not surprising that none of the parents seemed to attribute significant success to the sensory-motor portion of the program. On the other hand,

parents attributing changes to aspects of the diet and supplement component of the program is consistent with research on some dietary or supplement interventions showing a positive trend for efficacy in reducing severity of symptoms in some sub groups with neurobehavioral disorders (Rossignol & Frye, 2010). Many of the parents in the study seemed to perceive changes as being most strongly associated with the use of the biomedical aspects of Brain Balance. Also, specific parental comments about changes related to rhythm, coordination and academic/cognitive fluency could be correlated with the use of Interactive Metronome in the program. This finding is consistent with research on the Interactive Metronome (Taube, McGrew & Keith, 2007). Also, parents' observation of improvement in academics could be predicted from research regarding academic remediation of a learning difficulty (Weiser & Mathes, 2011) or use of Interactive Metronome (Taube, McGrew & Keith, 2007). Thus, parents' final judgement on how the program impacted their child seemed to be predicted from current research; that is that some subgroups of children in AD/HD and ASD will have a reduction in symptoms because of treatments with some biomedical interventions, Interactive Metronome and/or academic tutoring.

The five different categories of judgements that parents made about Brain Balance gave a small sample of parents' evaluative statements about the program. Overall it seems that their judgements point to the fact that for some individuals, *aspects* of this program may lead to improvements in symptoms of neurobehavioral disorders. These parents' judgements lead to implications related to practice and research. Topics to be explored which stem from these judgements are: assisting parents with decision making, importance of evaluation of programs, the evidence base around interventions and how different modalities of intervention are coordinated.

5.1.3 Impacts of Brain Balance on the children and parents. The documents reviewed in this study indicated that Brain Balance impacted the families in seven ways. Both the children and parents were impacted emotionally, there were impacts financially, on lifestyle and on relationships in the family. Additionally, there were impacts on the families use of standard therapies and in some cases on the child's functioning. The reporting of these findings contributes to expanding the dearth of research literature on Brain Balance and in particular how participants experience the effects of this intervention.

The program had an impact on the families' lifestyle, and relationships. These two themes were common to all participants. Lifestyle changes were a result of changes in activities related to electronics, exercise and diet related activities. Relationships were affected because of changes in family dynamics that happened to implement the program and in some cases because of changes in the child's functioning which allowed changes in interaction in the family. Many of the families interpreted these changes as ultimately positive but some experienced challenges because of the stress of changes in lifestyle or in relationships. This is important to note as families need to be prepared for or supported through dealing with changes in lifestyle or relationships brought about by an intervention.

Finances were also a prominent impact of the program. All families reported being impacted by the cost of the program. The implication of this is that funding determines who can access interventions. In Brain Balance's case it was not publically funded as it did not have the evidence base or professional consensus supporting its efficacy.

The emotional impacts of the program were both negative and positive for the parent and child. The negative reactions related to the stress at challenges from the program and challenges from lifestyle changes. These negative emotional reactions did not cause any serious repercussion in these families, although for some families this may not be the case as not everyone copes successfully. While positive reactions to the program, including hope and joy, resulted from positive progress or changes in the child. The final emotional impact of the program on these families related to their perception of changes in their child. For those who had improvements, they felt joy and satisfaction but for those who did not, they felt disappointment or heartache. A negative reaction appeared to have some residual effects on these families as they felt taken advantage of or let down by Brain Balance.

Brain Balance, also, impacted how parents used other therapies. Initially, the families put most other supports on hold while they did Brain Balance. While after the program families modified or resumed other therapies depending on results from the program. For one family that did not get results they pursued medication for their child for the first time. Not surprisingly, Bowker and colleagues (2011) found parents discontinue treatments (both evidence based or non-evidence based) when they do not see results. Those who got positive results modified or removed services/treatments that they had prior. For example, one family thought their child

improved enough to forfeit funding for autism services which included a behavioral therapist. Additionally, in the cases of positive results, some continued the lifestyle or dietary changes they had implemented with Brain Balance; that is they continued with exercise activities and diet changes.

The online documents of this study indicated that parents observed specific changes in their child from the program. Three of the parents in the study reported positive changes in their child as a result of their involvement in Brain Balance. Peter's social impairments, anxiety, low mood, inattentiveness and academic issues were improved. Luke's coordination, clumsiness, rhythm, ability to make inferences, ability to understand sarcasm/figures of speech, processing speed, ability to do academic work independently, reading and math fluency improved. Maggie's symptoms of severe autism improved with increases in language, empathetic reactions, social play with sibling, ability to follow instructions, ability to remain calm, reduction in rigidity and stereotypical behaviors. All of these changes were amazing to the parents and brought great happiness to them. The two parents whose children had no significant change or had a regression experienced a more detrimental impact from the program. These families had to cross off one more intervention that did not meet their needs to help their child. Furthermore they had no compensation for their effort, time or loss of money. One family thought their child was doing worse, as evident in his need for more special education time, and felt blamed by the center for this. For these families they did the best they could for their child. Their experience exemplifies the vulnerability of families of being taken advantage of (financially, time, emotionally) by interventions that have not been systematically evaluated. This study shows that there is variability in the impact of Brain Balance on the functioning of a child.

The observations these parents shared of the changes that occurred or did not in their children during this program indicated that for some there was an aspect or aspects of Brain Balance that was potentially effective in reducing symptoms in children with ASD, AD/HD or LD. This finding has implications for future research but also indicates a caution to parents about investing time and money into this program as a whole.

5.1.4 Motivations of parents doing Brain Balance. The parents who participated in Brain Balance in this study were motivated to do the program simply because they wanted to help their child. The findings indicated that parents were seeking meaningful change in their child's

functioning, that they were disappointed in previous therapies results, that their child's symptoms needed treatment and that they were following the successes of others with this program. The implication is that a parent's decision making is heavily impacted by the awareness of their child's needs and a persistent hope that they can find a better way to meet them.

Because chronic sorrow or the reoccurring awareness of the loss of typical functioning is part of parenting a child with an exceptionality (Green, 2006; Roos, 2002) parents will hope for treatments that bring their child closer to reaching their potential. These documents showed many examples of parents hoping for improved functioning in their child. They all conducted a search looking for ways to make this happen. This is consistent with wider research on parents of children with disability. For example, Kearney and Griffin (2001) describe a theme of parental defiance of their child's prognosis by pursuing therapies to overcome difficulties in the hope of success even in the face of professional advice that the difficulty was unchangeable. These parents preferred to live in hope of the possibility of some success and had great joy or felt more adaptive for trying (Kearney & Griffin, 2001).

When they hear of the success of others with a treatment this can be a powerful influence on their decision making. When comparing their slow progress or just coping through the use of present therapies, compared to amazing stories of radically reducing symptoms with Brain Balance, what parent could resist considering the possibility of doing the program? Online forums were full of parents searching for information on others experiences with treatments. They were looking for the opinions of their peers to figure out what to do for their child. They may see each other as credible reporters of the effects of therapies. Generally, other parents do not have vested interests in any particular therapy; they just want an effective one. That is why parent testimonials are influential in other parents' decision making for therapies. It is true that an individual case can generate the possibility that something significant happened for that individual but it is not a strong form of evidence to determine what exactly happened. As a result, interventions need to have more proof than just testimonials. This study is consistent in the fact that most parents do not consider empirical evidence when choosing an intervention but are influenced by other factors (Bowker et. al, 2011). Factors that have been found to influence parents' choice of intervention are their belief in the cause of the disorder, parenting style, lifestyle, access to services, the impact of media and the impact of testimonials (Bowker et.al,

2011). Parents' perceptions of treatments that work are more influenced by changes in the child's functioning than empirical research (Bowker et.al, 2011); therefore testimonial of peers may provide a model that encourages a try and see approach to choosing interventions.

The implication of what motivates a parent to choose a therapy is that they are vulnerable to therapies that claim radical improvements because of their sense of responsibility to their child and an unceasing hope for improvements. Also, the power of a testimonial to influence is significant and needs to be tempered with other evidence that is more systematic. Because of changes in wider culture making the internet a forum to seek information, this type of dialogue needs to be made available to individuals on the internet.

5.1.5 Motivations for writing online. All the parents who wrote about Brain Balance online seemed to be doing so with the main aim of helping other parents. Beyond helping other parents they also wrote online to document what happened, to communicate with relevant others such as their personal circle, stakeholders and advocate with professionals and funders. It was clear that the parents in this study used the internet as a source of information, as a community of support and as a means to influence and dialogue with others around the issues that pertained to their child's disorder.

In many ways these parents wrote their stories in a way so that other stakeholders (i.e. parents, funders) could use their description as a source to consider the merits of Brain Balance. Merit is a judgement of value of the quality of a program overall or in a particular area (Mertens, 2010). It seems that these parents wrote to help other parents learn what their experience was like and to use this to inform their subsequent decisions. It is important to note that the information these parents provided is the type of information that is sought when qualitative methods are used in evaluation of interventions (Noyes, 2010). Noyes discusses the rise of qualitative research to be included as a source of evidence in Cochrane intervention reviews. The Cochrane intervention review provides information about the effects of interventions and they now recognize the need for information regarding an intervention from the participants perspective using qualitative methodologies (how they experience their condition, how they make decisions on treatment) (Noyes, 2010). Thus, these parents' online postings are very relevant to those who research neurobehavioral disorders.

These parents' choice to write online and share their experience as their gift to the wider community to help evaluate Brain Balance and may generate ideas related to interventions. They shared their own 'experiment' so others could learn from the experience. The findings generated from this study have implications for practice and research.

5.2 Implications For Practice

The findings that were generated from analysing these online documents are ripe with implications for parents and professionals. Implications of this study relate to how achievable are therapies with multiple modalities; preliminary evaluative information on Brain Balance; vulnerability of parents to claims with testimonials and the need for parents to give feedback on interventions.

5.2.1 Multiple modalities in therapy. Brain Balance is an example of an intervention that has multiple modalities; as a result it puts greater demands on a client. In this study parents expressed challenges and stress related to coordinating all the demands of the program and having the time in their life generally to do everything that was required. One parent even implied that Brain Balance blamed her for her son not having success. It could be inferred from this that the parent may have had trouble implementing the home part of the program. This parent did not express this sentiment but other parents did indicate this sentiment. They all ended the program with a great sense of relief from the demands. It must be understood that the lives of some individuals with neurobehavioral disorders are more stressful than average (Rao & Beidel, 2009; Dabrowska & Pisula, 2010); therefore interventions should be careful not to unduly add to the stress of these individuals. With this in mind when an intervention needs to be in multiple modalities (whether it is for AD/HD or Autism) practitioners and parents need to think about what is realistic and practical for the particular client. It may be prudent to choose high priority or high impact areas to do first and then to add others in an incremental step by step fashion. In other words consecutively over a period of time rather than all at once. In this way stress will be reduced and success is more likely.

Research or clinical judgement can determine what the order of intervention should be. For example, in the case of ASD it may be prudent to use dietary/supplements first and then behavior therapy subsequently to get the best results in some cases (Herbert, 2005). Multimodal interventions can be necessary when a problem is multi-faceted or has complex etiology.

Additionally, providing treatment in multiple modalities can allow for a more holistic/comprehensive treatment. The perceived comprehensiveness of Brain Balance was one thing a number of the parents appreciated about the program. This finding implies the need for the coordination of services when a client has a complex disorder, as this reduces the stress of the client or family. Practitioners who provide services for individuals with neurobehavioral disorders need to attend to providing interventions in a comprehensive but achievable format as it has impact on client stress and success.

5.2.2 Preliminary evaluation. Because many of the parents made judgements about their experience with Brain Balance, the findings of this study provide information meaningful for an evaluation of Brain Balance. This information could contribute to an evaluation of the program or serve as information for other parents considering Brain Balance. Some significant judgements parents in this study made about the program were that it was expensive and of questionable value considering the service they actually received. Some centers made mistakes in labelling of a supplement, in recommending the dose of a supplement, and in teaching how to do exercises. These types of mistakes reduce the quality of the program and could cause injury or harm. A parent also felt they had been doing some exercises wrong almost the whole time and she felt ripped off. Additionally, a center made changes in how the reintroduction of food in an elimination diet was done and the parent perceived this to be manipulative. That is she felt she had to go through a difficult process and the center was now using a different standard for others, so either they were manipulating or not knowing what they were doing? Parents' comments also alluded to the fact that some centers had a better reputation with more severe clients. Another parent felt there was an inconsistency in marketed ideas about the program and how it was actually done- she felt they were disorganized in administration of the program. All these comments speak to the quality of programming in a center and indicate that Brain Balance can improve in regulating the quality of its programs.

In terms of parents judgements on the program overall, they indicated that it was a difficult program to participate in. Specifically, that it was very demanding of time and effort. Another parent felt that the program was overpriced and borrowing from other therapies and that a person could just seek out a relevant aspect of the program without doing the whole thing. This is an important finding as it indicates that a participant of the program is aware that some aspects

of Brain Balance that are perceived as effective are available in a more affordable form in the helping community. Additionally, one parent cautioned that the outcomes are variable and positive results do not always happen.

Finally, the parents' judgement on the outcome of the program, indicate that there was a wide variation in outcomes. Variation could be expected because of the heterogeneity of clients, yet they are supposedly customizing the process for each client. Some had positive significant changes and others had no significant change or seemed to worsen. Although some degree of variation in outcomes can be expected for any intervention, with this much degree in variation of outcome it is apparent that Brain Balance needs to do the research into what is really working versus what is not in this program. The description of the judgements of the parents in the study's documents is valuable to help others initially evaluate Brain Balance.

5.2.3 Vulnerability of parents. Another critical implication of this study is that parents seeking to make a decision about what intervention to pursue for their child are vulnerable to the influence of testimonials about interventions and do not necessarily have information on how to evaluate the claims made by promoters. Testimonials can speak to people at a more emotional level and depict positive results. What is left out are the details of who this intervention is suited for, information on any of the individuals who achieved marginal or no positive results and solid evidence based on systematic study may be lacking. Granted testimonials do put a human face on more clinical sounding information, give other valuable information and act as a 'reference'; they add credibility to an intervention but they do not provide strong proof of the effectiveness of an intervention.

In addition to testimonials, the theory explaining how Brain Balance works was influential in convincing parents to get involved with Brain Balance. In considering Brain Balance's claims of its exercises balancing the cerebral hemispheres, parents may realize from this study that this claim is an oversimplification of current research in neurology and that the claim of balancing hemispheres is inconsistent with the exercises that are part of the program. That is some exercises target more than the cerebral hemispheres. Although, many of Melillo's claims are scientific sounding they are only working hypotheses still unproven in research.

Professionals have a duty to assist parents or clients in interpreting the claims of interventions and the interest around them that comes from testimonials. Professionals are in the place to do this when parents come to them looking for this advice. The difficulty is that there are other information sources where parents/clients may seek information, such as the internet. It seems that professionals need to take an active role in producing reputable information to parents that shares research findings on empirically supported treatments and encouragement to seek consultation with professionals in relevant areas of expertise.

Professionals have a duty to act with evidence based practice in mind and can convey this online. Evidence based practice consists of the integration of the best available research with clinical expertise in the context of patient characteristics, culture and preferences (Stelle et.al, 2008). Professionals can contribute to the awareness of the public to the issue of evidence based practice by making resources available online. Currently on the internet, sites can be found where professionals blog about their area of research (Dr. K. McGrew at www.themindhub.com), where professional bodies publish information (www.cpa.ca, or www.apa.org) or sites professionally moderated to inform parents (www.autismspeaks.org). This practice will need to continue. Beyond professionals presence online, it is evident that the parents who write online want to give feedback on interventions to help vulnerable others, as well.

5.2.4 Parental feedback. With the awareness that parents wrote online to contribute to evaluating Brain Balance, a further way of addressing the vulnerability of parents to the claims of new experimental interventions is for professionals to provide a feedback or a check in mechanism in their work with clients. Because professionals can recognize that parents of children with exceptionality are motivated to search for the best possible intervention, it could be helpful to provide a feedback mechanism where the parent can state their perception on how things are progressing. In psychotherapy, Miller, Duncan and Hubble (2004) designed a process that involves collecting feedback from clients as a means of improving outcomes of therapy. It involves regularly seeking feedback from the client about the therapeutic alliance (working relationship) and the experience of change from the therapy (Miller et.al, 2004). This feedback mechanism in multiple studies resulted in improving the retention of clients and the outcome of therapies (Miller et.al, 2004). Similarly, professionals who work with those with neurobehavioral disorders may implement a similar dialogue with their clients. During this dialogue issues around

the intervention can be discussed – how to trouble shoot things to improve process, how to understand what research is saying about the best course of intervention, and goal planning around next steps/supports. In other words, by providing a mechanism for parents to talk to professionals about their experience of interventions specifically and generally, it can help parents in their decision making and satisfaction or commitment to empirically supported interventions. In this way professionals can assist parents who are vulnerable to claims of unproven interventions while respecting their autonomy to choose where they seek help.

Finally, given that Brain Balance can be seen as an experimental intervention that does not meet the standards of evidence-based practice parents and professionals are challenged to make sense of why some individuals seemed to benefit from the program. The theoretical explanation behind Brain Balance as being applicable to all neurobehavioral disorders is unproven as is the efficacy of this program as a whole; but individual components of the program may show some promise in addressing aspects of these disorders. Further research would be valuable in determining what components are helpful and it is then, when known, that a strong rationale for a multimodal program or coordination of interventions could be proposed. Until then parents are advised to seek targeted intervention from professional sources that address their child's diverse needs.

5.3 Limitations

Although this study produced an extensive description regarding questions about Brain Balance, it was limited in its findings because of aspects of the research design and the use of online documents as a data source. When considering the findings of this study these limitations are to be kept in mind.

The research design affected the type of findings generated, who the findings apply to and the credibility/reliability of the findings. While a qualitative research design is well suited to understand processes in the program and judgements made by the parents, it does not allow the drawing of any conclusions about the efficacy of Brain Balance. This type of research design cannot answer the question of Does Brain Balance Work? Instead the study generates a few hypotheses for future study that could investigate the efficacy of aspects of the program; therefore future research could address the causes of change related to aspects of this program. Additionally, the findings are not necessarily generally representative of typical participants of

Brain Balance; but are a description of a range of individuals' experiences which may be transferable to someone else's situation, if it is similar. That is through thick description a reader can consider if the findings are applicable to their own situation. These findings are not generalizable, that is it cannot be assumed that others who participate in Brain Balance will get similar results or have similar experiences. The sample used in this study was not large enough to apply these findings to participants generally of Brain Balance; instead information rich sources with a range of experiences were sought. As a result, a range of experiences were depicted in the findings not necessarily a general or typical experience. Also, the interpretations of this study were limited by this author's analysis as I was not able to check my interpretations with the authors of the documents to clarify that my interpretations were accurate to their experience. This limitation of the research design, results in less reassurance of the credibility of my interpretations. To attempt to ensure the credibility of my interpretations I attempted to stay close to the way the documents were written. A member check or interview with authors would have added more credibility to the findings. These three areas of research design limit the findings of this study to a description that stays close to the data.

Similarly, the use of internet documents also presents unique challenges to the study. Because the documents were from online sources, the authenticity of the documents was not verified and the assumption was made that the authors were first hand participants who were legitimately sharing their experiences. There is the danger when using online sources that the author has other motives and is not truly who they espouse to be. In the case of an intervention it is wise to be skeptical of the authenticity of online documents. I felt that the level of description that these blogs contained lent to their authenticity. Also, because I did not solicit them, I felt that it was likely that they were genuine. Yet, beyond my impressions of the documents no official process of authenticating the documents was made. Also, there were a limited number of documents regarding Brain Balance, particularly in the negative view; therefore the sample was biased by what was available at the time of the study. This highlights the issue of a general bias in a sample in internet research of only collecting the views of those in the population with access to the use of the internet and those who have the ability to use it. This results in only certain types of individuals to be part of the study, which can skew the results to a certain group in society. Similarly, having very few short postings on negative viewpoints, limited the amount of detail I could learn from those individuals with negative experiences around the program. It would have

been necessary to attempt to contact those individuals, who did post a warning, to interview them to understand their viewpoint more fully. Thus, using other means of seeking documents or participants could have allowed for a wider population of individuals from which to take a sample and may have resulted in more detailed information about negative experiences with the program. Despite the studies limitations they have generated implications for practice and future research.

5.4 Future Research

The description produced from the analysis of these six documents is a catalyst for future research. The findings provide support for further research in cognitive rehabilitation methods, biomedical treatments, the internet as self-help tool and the effect of client feedback as a process in interventions for neurobehavioral disorders.

It is a trend of research currently to investigate biomedical approaches in autism (Rossignol & Frye, 2010) and wider mental health to a smaller degree (Stevens et.al, 2011); this study lends support to the positive trend in biomedical research. The findings of this study although descriptive in nature lead to the hypothesis that changes in some of the children in this study likely were attributable to the diet changes and nutritional supplementation the children received. The parents' comments indicate that their observations attribute the changes in their child to the diet or supplement intervention. In one case, the parent saw a return of symptoms when she reintroduced an offending food back into the child's diet and the remittance of symptoms when she removed it. The other parent had a similar experience of seeing reductions of symptoms with removal of offending foods and the return of symptoms when she tried to reintroduce a food. A third parent whose child with autism improved radically attributed her gains to the program generally, yet a close analysis of the time line of reported changes coincided with the introduction of specific supplements that were recommended from lab testing. In trying to make sense of the very real and substantial changes parents reported as a result of doing Brain Balance it is reasonable from the data to hypothesis that some of the changes that come out of Brain Balance are related to the nutritional aspect of the program. Thus, further research should investigate the use of lab recommended diet and supplement interventions for AD/HD, ASD and related conditions.

Additionally, some of the data derived from parental online documents about Brain Balance indicated that cognitive rehabilitation in the form of Interactive Metronome is also an area that should be researched further. All the children with positive results received the IM therapy and one parent in particular describes a change of symptomology that according to research (Taube, McGrew & Keith, 2007) could be attributed to Interactive Metronome. This parent described her son's change in academic fluency and in athletic coordination in activities requiring sequencing and timing. He was a child who previously could not skip rope but at a certain point in the program he was able to pick up a rope and skip competently without practice. The child was amazed and he said "You know what I figured out? There's a rhythm, and if you get the rope going to a beat, you're body just knows what to do." This data supports the hypothesis that Interactive Metronome may be an aspect of the Brain Balance program that is efficacious. To further explore this hypothesis research should continue on Interactive Metronome for children with neurobehavioral disorders. Alternatively, some may feel the child's improvement in gross motor skills could be attributed to the sensory/motor exercises that specifically address core muscles. This is also a hypothesis to be investigated as gross and fine motor issues should not be ignored, as improvements in these areas can contribute to more independence, self-help skills, confidence and emotional well-being (Reiersen et.al, 2008; Blondis, 1999). Essentially, further research can contribute to understanding what part of Brain Balance contributes to change in some children.

This study also indicates that further research in examining the internet as a source and process of self-help is prudent. A prominent finding in this study is that parents used the internet to help other parents and to communicate with others around the issue of their child's disorder. In a sense this is a sign that parents of exceptional children go to the internet for information, to share information and support with other parents. Research in this area could shed light on what needs a parent of an exceptional child has that could be met by the internet. Or in what way can parents of exceptional children best derive support from the internet.

The parents, who blogged about their experiences with Brain Balance, demonstrated a need to give feedback about this intervention. Future research could be designed to see what effect providing a mechanism or process for parental feedback might have on outcomes for neurobehavioral interventions. This research could contribute to parents' satisfaction with

interventions or provide researchers with understandings of the processes and effects of interventions that are not typically studied but contribute to determining what interventions are used.

Thus, the findings of this study encourage more research in nutritional approaches, Interactive Metronome, use of internet for self-help/support and the effects of parental feedback about interventions for neurobehavioral disorders.

5.5 Conclusion

The description produced from six parental online documents about Brain Balance was possible because of the contribution of six parents sharing their story. They all were motivated to help their child and to help and dialogue with fellow parents who have exceptional children. My producing this description joins with their purpose of helping families with exceptional children. The rich description produced by this study is helpful in understanding how six families experienced Brain Balance. Brain Balance is an experimental intervention which is controversial because of aspects of its theory and practice. The parents' judgements about the program indicate that they found it expensive and difficult with results ranging from significant improvements to no significant change. Reflection on the findings highlights the need to consider stress from interventions, especially multimodal intervention, the need clients have to give feedback about interventions and professionals responsibility to assist the public in decision making about interventions. Hypothesis generated from this study encourage future research in biomedical/nutritional approaches and cognitive rehabilitation for neurobehavioral disorders. The potential for application from these research areas is ripe with potential. These are hopeful times.

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